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# The Desire for Hastened Death in Home Hospice Care

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University of Pennsylvania, swichman@sp2.upenn.edu

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# The Desire for Hastened Death in Home Hospice Care

## Abstract

### The Desire for Hastened Death in Home Hospice Care

**Introduction:** The desire for hastened death describes the desire of a terminally ill patient to die sooner than anticipated through disease progression. There is growing awareness that this phenomenon is not unusual among individuals facing the end of life. Though research on this topic is expanding, the majority of studies focus on inpatient populations, with limited investigation into the challenges specific to the home hospice experience.

**Significance:** Annually, forty percent of deaths in the United States represent hospice patients. Hospice social workers are responsible for addressing the mental health needs of their patients. There are few practice guidelines or concrete frameworks for social work assessment and intervention when a patient expresses the “desire to hasten death.” Understanding the circumstances that influence “hastened death” in home hospice can provide a foundation for future development of social work practice guidelines and interventions to improve services and better support the complex needs of patients who choose to die at home.

**Objective:** This study aimed to enhance understanding about what motivates one’s “desire for hastened death” in the unique context of the home hospice setting. This research used in-depth interviews to elicit patient perspectives and regarding factors that have contributed to contemplating hastened death.

**Methodology:** This study consisted of cross-sectional, semi-structured interviews with home hospice patients. Potential subjects were recruited through a New York City hospice agency. Hospice social workers provided referrals for this study.

**Results:** Fifty-five referrals were made for this study. Of those, twenty-seven patients did not meet eligibility criteria, twenty-seven patients were lost to follow up, and one patient volunteered to be interviewed.

**Discussion:** The interview indicated that this patient had contemplated the idea of hastened death, and was aware of the general discussion about “right to die” legislation. The respondent indicated that she was fearful of having future symptom issues, and being home alone and unable to access help when these symptom needs arose. She also spoke about the challenge of navigating her relationship with her daughter as her daughter took on more responsibility as caregiver. Given that the scope of this study was limited to its one respondent, results are not generalizable. However, this patient’s experience reinforces the impact of many of the factors discussed in the current literature.

**Practice Guidelines:** This study presents a review of current practice guidelines and identifies areas of assessment and intervention that would be most useful for clinicians in home hospice care. Given the multifactorial nature of the “desire for hastened death,” social work assessment should consider a “biopsychosocial-spiritual” approach. Recommended therapeutic interventions include aspects of cognitive behavioral therapy and mindfulness practice, as well as newer therapies developed from research on the “desire for hastened death.”

**Implications for Social Work Practice:** Social workers need more focused training and education about the “desire for hastened death.” It is important that they understand both the etiology of “desire to die” statements, and how to assess and intervene appropriately in order to understand and support their home hospice patients.

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Zvi D. Gellis, Ph.D

**Second Advisor**

Tracy A. Schroepfer, PhD

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**The Desire for Hastened Death in Home Hospice Care**

Sarah Wichman

University of Pennsylvania

School of Social Policy and Practice

Doctorate of Clinical Social Work Dissertation

Dissertation Chair: Dr. Zvi Gellis

Committee Member: Dr. Tracy Schroepfer

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To my friends, I've missed you! I'm so grateful for your love, laughter, understanding and support.

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## **Chapter 1: Problem Statement**

### **1.1 Incidence and Prevalence**

In 2013 there were 2.597 million recorded deaths in the United States. Of these deaths, 1.059 million represented terminally ill patients receiving hospice care, meaning that over 40% of individuals who died in the United States were receiving hospice services (National Hospice and Palliative Care Organization, 2014). This number continues to grow as the population ages and the discussion of options for care at the end of life expand. Hospice is a holistic health care model for terminally ill individuals who are no longer pursuing curative medical treatments. An interdisciplinary team of doctors, nurses, social workers, chaplains, home health aides and bereavement counselors collaborates to address physical, psychosocial, spiritual and practical needs of patients and their families. Hospice care is focused on patients' quality of life, and services may be provided in patients' homes, nursing homes, and inpatient hospice units (National Hospice and Palliative Care Organization, 2013).

A controversial topic in end of life care focuses on a terminally ill individual's right to end his or her life. This issue has received increasing attention as the national discussion about right to die legislation has broadened. There is a growing awareness that it is not unusual for terminally ill patients to "desire to hasten death" (Altilio & Otis-Green, 2011; Arnold, Artin, Person, & Griffith, 2004; Chochinov et al., 1995; Ganzini, Johnston, McFarland, Tolle, & Lee, 1998; O'Mahony et al., 2005; Rosenfeld et al., 2006). This concept describes the desire of a terminally ill patient to die sooner than anticipated through disease progression (Altilio & Otis-Green, 2011). Studies have reported a wide

range of results related to the prevalence of the “desire to hasten death,” from 3-55% among terminally ill individuals (Wilson et al., 2014).

## **1.2 Significance**

The challenge of addressing the “desire to hasten death” is elevated in the home hospice setting. Home hospice care comprises a significant majority of overall hospice services in the United States. In 2012, Routine Home Care services for patients in private residences amounted to approximately 72% of total days billed by hospice (National Hospice and Palliative Care Organization, 2013). The home-based hospice model is unique in that it relies upon a patient’s loved ones for the majority of day-to-day patient care. An interdisciplinary team of hospice medical staff makes regular home visits and closely follows patients and families. Clinicians are also available to address urgent issues as needed. However, the home hospice team’s ability to monitor and support a patient who may be considering a hastened death is very limited compared to an inpatient setting with around-the-clock staff.

Hospice social workers are responsible for addressing the mental health needs of their patients. There are few practice guidelines or concrete frameworks for social work assessment and intervention when a patient expresses the “desire to hasten death.” While research on this topic is expanding, the primary focus has been on inpatient populations, with few studies that exclusively investigate the home hospice environment (Anguiano, Mayer, Piven, & Rosenstein, 2012; Rosenfeld, 2000a). The existing empirical research provides insight regarding the concept of the “desire for hastened death,” but the relevance of inpatient data for the hundreds of thousands of home hospice patients requires further exploration. In order to provide the best possible care and attention to

patients who choose to die at home, further study in this area is necessary. Understanding the circumstances that influence “hastened death” in home hospice can provide a foundation for future development of social work practice guidelines and interventions to improve services and better support the complex needs of patients who choose to die at home.

### **1.3 Purpose of Study**

The aim of this exploratory study is to enhance understanding about what motivates one’s “desire to hasten death” in the unique context of the home hospice setting. This study will focus on participants who have made previous expressions about desiring hastened death. This research will use in-depth interviews to elicit patient perspectives and personal insights regarding factors that have contributed to contemplating hastened death.

## **Chapter 2: Hospice Background**

### **2.1 Hospice Philosophy**

Hospice is a concept of care for terminally ill patients who are no longer pursuing curative medical interventions, either by choice, or because there are no further options available. Hospice focuses on improving quality of life rather than extending life (National Hospice and Palliative Care Organization, 2014). It is a holistic care model designed to address the unique physical, psychological, and spiritual needs of an individual patient, and support his or her loved ones. Hospice also provides education and counseling to patients and families regarding death and dying, and offers bereavement services after a patient’s death. Care is provided by an interdisciplinary team that includes

social workers, nurses, physicians, chaplains, volunteers and home health aides. While hospice can be provided in freestanding hospice facilities, hospitals, nursing homes, and other long-term care facilities, the majority of hospice services are delivered at home (National Hospice and Palliative Care Organization, 2014).

To meet hospice eligibility requirements, two physicians must sign a certificate attesting that an individual is likely to die from illness within six months. Medicare regulations mandate that hospice services should be available to any patient in need of care, regardless of one's ability to cover costs of care (Centers for Medicare and Medicaid Services, 2014; Weisenfluh & Csikai, 2013). Hospice provides services to patients of all ages and ethnicities, though in 2012, 83.4% of patients were 65 or older, and 81.5% of all hospice patients were Caucasian (National Hospice and Palliative Care Organization, 2013)

## **2.2 Hospice History**

### **Origins: Britain**

Hospice origins can be traced back to the fourth century, where the Latin word *hospitium*, translated as guesthouse, was used to describe a place to rest for religious travelers who were tired or ill (Altilio & Otis-Green, 2011, Berzoff & Silverman, 2004; Clark, 2001) However, the foundations for what is considered the modern hospice movement did not emerge until much later. Dame Cicely Saunders is universally credited as the architect of the modern hospice philosophy. Originally employed as a nurse, Dame Cicely later trained to become a "lady almoner," which was that period's term for today's social worker (Berzoff & Silverman, 2004; Richmond, 2005). In 1948, while employed at Archway Hospital, she worked closely with a terminally ill 40-year-old Polish immigrant,

David Tasma. She observed that the hospital environment was limited in its ability to support the unique psychological and spiritual needs Mr. Tasma faced as he was dying (Berzoff & Silverman, 2004). Saunders' work with Mr. Tasma inspired her to explore new and better ways to care for the dying, and this became her life's mission.

Dame Cicely was advised by a physician that she would not be able to communicate her ideas in her current position, and that she would be best able to pursue her goals as a doctor (National Hospice and Palliative Care Organization, 2014; Richmond, 2005). Heeding this advice, Saunders studied at St. Thomas's Hospital Medical School and completed her surgical training in 1957. From that point, Saunders focused on education and advancement in end of life care. She introduced the idea of "total pain," which emphasized the need to address emotional, social, and spiritual distress, along with a patient's physical pain (Connor, 2007; Richmond, 2005). In 1967, Dame Cicely realized her dream of opening the first modern hospice residence. St. Christopher's Hospice in London continues to care for dying patients today, and serves as a center for end of life education and advocacy.

### **Origins: United States**

Saunders' groundbreaking work quickly attracted international interest. In 1963, she traveled to the United States at the invitation of Florence Wald, Dean of the School of Nursing at Yale University. She made subsequent visits in 1965 and 1966, and these visits are considered the foundation of the United States hospice movement (Clark, 2001; Connor, 2007). In 1968, Wald went to England to spend a year at St. Christopher's Hospice and learn about the provision of hospice care (National Hospice and Palliative Care Organization, 2014). By 1974, Wald, then back in Connecticut, was instrumental in

opening the first U.S. hospice, the Connecticut Hospice. In Branford, CT, this facility provided services to terminally ill patients in their homes.

The late 1960's also saw the publication of the influential book titled *On Death and Dying* (Kubler-Ross, 1969). Elizabeth Kubler-Ross challenged the idea that institutions should be central to the provision of end of life care, and identified the need for terminal care at home. The author, a psychiatrist, offered insights gleaned through hundreds of interviews with terminally ill patients. This groundbreaking book encouraged readers to reexamine their own, as well as societal, relationships with death. Kubler-Ross (1969) provided insight into the psychology of death and highlighted the importance of self-determination.

### **Origins: U.S. Legislation**

In response to the growing interest in end of life issues and hospice care, the first legislative support for hospice care was introduced in 1974, though without success (Buck, 2011; National Hospice and Palliative Care Organization, 2014). By 1979, the Health Care Financing Administration (HCFA) piloted programs at 26 U.S. hospices to better understand the role and cost of these services. Responding to positive findings regarding the clinical and economic value of hospice care, Congress enacted a provisional Medicare Hospice Benefit in 1982, to be reassessed in three years. This was the first time federal funding was used to cover the cost of hospice programs (Altilio & Otis-Green, 2011; Connor, 2007). This benefit was, however, limited by the small number of hospices that were certified Medicare providers (Buck, 2011). The provisional Hospice Benefit was reviewed and made permanent in 1986. By 1991, hospice care was added to the benefit package for United States Veterans, and by 1993, as part of President



Clinton's health care reforms, hospice became a nationally guaranteed benefit (Buck, 2011; Harper, 2011; National Hospice and Palliative Care Organization, 2014).

Over the next decade, the United States saw dramatic growth in hospice services, and by 2004, over one million patients were receiving hospice care annually (National Hospice and Palliative Care Organization, 2014). Two years later, the American Board of Medical Specialties recognized hospice and palliative medicine as a specialty (Connor, 2007). Today, more than 6,100 hospice providers are caring for over 1.6 million patients nationwide (National Hospice and Palliative Care Organization, 2015).

### **2.3 Hospice Social Work Role**

The role of hospice social workers is dynamic and as varied as the clients they serve. They act as counselors, advocates and educators for the patients and families under their care. Social workers are the primary providers of mental health services for hospice patients (Weisenfluh & Csikai, 2013). In 2008, the National Hospice and Palliative Care Organization (NHPCO) published guidelines for social workers in hospice. These guidelines include completion of an initial social work assessment, development of a plan of care in collaboration with the interdisciplinary team, provision of ongoing social services, determining need-based visit frequency, ongoing goal-oriented intervention, involvement in establishing agency policies, education, bereavement support, and advocacy.

Hospice social work encompasses all aspects of the "biopsychosocial-spiritual" approach to care that is core to social work practice (Mackelprang & Mackelprang, 2005). There has been active discussion in the literature about the social work role in hospice (Altilio & Otis-Green, 2011, Berzoff & Silverman, 2004; Christ & Sormanti,

1999; Gwyther et al., 2005; Kramer, Christ, Bern-Klug, & Francoeur, 2005; Weisenfluh & Csikai, 2013). There are clear parallels between the holistic, patient-centered models fundamental to social work and hospice philosophies, and it is notable that through her experiences as a social worker, Cicely Saunders first conceptualized hospice (Berzoff & Silverman, 2004; Gwyther et al., 2005; Kramer, Christ, Bern-Klug, & Francoeur, 2005).

Hospice social workers frequently counsel patients and caregivers through difficult decision making related to advance directives, pursuit of medical interventions, and goals for patient care. These discussions may yield complex ethical challenges, and social workers then become instrumental in helping to navigate the legal and bioethical issues that arise (Gwyther et al., 2005; Kramer, Christ, Bern-Klug, & Francoeur, 2005; Mackelprang & Mackelprang, 2005). One such challenge is a patient's expression of his or her "desire to hasten death." Social workers are the clinicians responsible for assessment and intervention with these patients, and both clinician and client would benefit from further insight regarding the issues that precipitate such desires. Research that can lead to more clearly defined practice guidelines and cohesive clinical education is a need frequently identified in the literature (Christ & Sormanti, 1999; Csikai, Roth, & Moore, 2004; Kramer, Christ, Bern-Klug, & Francoeur, 2005; MacDonald, 1991).

## **2.4 Hospice Home-Based Care**

Home-based hospice care is a holistic, patient-centered approach that embodies many principles also fundamental in social work practice (Altilio & Otis-Green, 2011). Like all hospice care, home-based services are provided by an interdisciplinary team of clinicians to address the physical, emotional, spiritual and concrete service needs of patients and their loved ones. Medicare regulations mandate that all hospices teams

include a physician, registered nurse, social worker, spiritual counselor, home health aides, volunteers, and bereavement counselors. Home-based hospice services must also offer a 24-hour on-call service to address any urgent concerns or questions that arise after hours, and when team members are not available (Centers for Medicare and Medicaid Services, 2014). Clinician visit frequencies are tailored to the needs of an individual patient and family, and interdisciplinary team members collaborate to address client needs as they arise.

Home hospice services have limitations, and team members are only present in a patient's home a fraction of the time relative to other informal caregivers. Hospice depends on these caregivers, who might be family members, friends, or neighbors to oversee and provide all patient care if a patient is unable to care for himself or herself. This includes responsibilities such as medication administration, bathing, meals, and tasks such as wound care as needed. Caregivers are not usually trained medical professionals, and need to learn how to provide this type of care. A critical part of the hospice team's role is to provide education, guidance, and support to caregivers as they take on these roles (Berzoff & Silverman, 2004). This dynamic is strikingly different from an inpatient setting, such as a hospital, hospice inpatient unit, or nursing home, where the responsibility of managing patient care shifts from familial or social networks to trained medical staff. Given these varied sites and approaches for the provision of end of life care, it is crucial to pursue setting-specific research to further explore the impact of each environment. This is particularly important in home hospice, which has been underrepresented in the literature.

## **Chapter 3: Review of Research Studies**

### **3.1 Hospice Patients and the Desire For Hastened Death**

In the context of terminal illness, the literature refers to thoughts of ending one's life as the wish, or desire, for hastened death. The "desire to hasten death" is a recognized phenomenon (Altilio & Otis-Green, 2011; Anguiano, Mayer, Piven, & Rosenstein, 2012; Arnold, Artin, Person, & Griffith, 2004; Block & Billings, 1994; Breitbart, Gibson, Poppito, & Berg, 2004; Chochinov et al., 1995; Branigan, 2015). It is broadly defined as a patient's desire to die sooner than anticipated through natural disease progression (Jones, Huggins, Rydall, & Rodin, 2003). The term "desire for hastened death" has been used throughout the research, but lacks any consensus with regard to conceptual framework (Rosenfeld, 2000c; Schroepfer, 2006). The "desire for hastened death" has been used to describe a spectrum of patient views, from fleeting thoughts about hastening death, to active pursuit of means to end one's life (Altilio & Otis-Green, 2011; Nissim, Gagliese, & Rodin, 2009; O'Mahony et al., 2005; Schroepfer, 2006). Some analyses characterize passive thoughts of "hastening death" as an expression of distress or communication of unmet needs (Achille, 2003; Block & Billings, 1994; Nissim, 2008; Van Loon, 1999).

The other end of the spectrum describes those patients who choose to end their lives by suicide, physician-assisted death (PAD), or euthanasia. Previously referred to as physician-assisted suicide (PAS), PAD has recently replaced PAS in the literature and is considered a more accurate term (Quill, Back, & Block, 2016). This study will use the currently accepted term, PAD, except when presenting older studies that relied upon the term PAS. PAD occurs when a physician provides a terminally ill patient with a lethal

prescription with the expectation that the patient will use this medication to end his or her life. PAD requires that a patient have the cognitive capacity to make this decision, as well as the physical ability to self-administer the lethal dose. PAD is voluntary and requires a patient to initiate the request and give consent (Altilio & Otis-Green, 2011; Rosenfeld, 2000c). PAD is legal in five U.S. states. Euthanasia describes an intervention initiated by a physician, or other health care provider, whereby the practitioner takes deliberate action to end a patient's life (such as administering a lethal injection) (Rosenfeld, 2000c). Though euthanasia does not require patient consent, in the countries where the practice is currently legal, it is predominantly initiated at the request of the patient (Norwood, Kimsma, & Battin, 2009). However, since consent is technically not required, opponents of euthanasia cite the risk of a 'slippery slope,' allowing the possibility that a practitioner may end a patient's life against his or her will (Norwood, Kimsma, & Battin, 2009). Euthanasia is illegal in the United States (Rosenfeld, 2000c).

Euthanasia and PAD represent very specific, active manifestations of the "desire to hasten death," which can also refer to passive thoughts and fears about disease progression. Decisions to withhold or withdraw life-sustaining treatments such as dialysis, antibiotics, and artificial nutrition and hydration are also included within this continuum, as is voluntary cessation of food and fluid (Rosenfeld, 2000c; Schroepfer, 2006). The "desire for hastened death" is an ambiguous term that may describe any or all of these scenarios, and offers no distinction regarding the character or acuity of the desire (Altilio & Otis-Green, 2011; Cohen, Dobscha, Hails, Pekow, & Chochinov, 2002; O'Mahony et al., 2005; Rosenfeld, 2000a).

Conceptualizing the "desire for hastened death" is further confounded by the

considerable variations in research methodology and results (Nissim, Gagliese, & Rodin, 2009; Rosenfeld, 2000b; Schroepfer, 2006). Some studies attempt to assess current “desire for hastened death” through inquiring about present moment feelings (Chochinov et al., 1995; Jones, Huggins, Rydall, & Rodin, 2003; Rodin et al., 2007; Rosenfeld et al., 1999). Other research has assessed the “desire to hasten death” through the use of hypothetical future scenarios (Emanuel, Fairclough, & Emanuel, 2000; Ganzini, Johnston, McFarland, Tolle, & Lee, 1998). Retrospective studies have also elicited information about patients who made the decision to hasten death (Back et al., 2002; Bharucha et al., 2003; George, 2002). Studies have included patients in varying stages of illness and in different care settings (Nissim, Gagliese, & Rodin, 2009; Schroepfer, 2006; Wilson et al., 2007). There have been few longitudinal studies, but those published have highlighted the inconsistent nature of one’s “desire for hastened death,” and observed that a significant number of subjects changed their minds in follow up inquiries (Chochinov et al., 1995; Emanuel, Fairclough, & Emanuel, 2000; Nissim, Gagliese, & Rodin, 2009). The multitude of approaches to studying this subject has resulted in substantial discrepancies in the data. This is particularly evident in analysis of the reported prevalence of the “desire to hasten death,” where findings have ranged from 3-55% (Wilson et al., 2014).

There have been limited attempts to establish a more precise framework for the “desire for hastened death” (Monforte-Royo, Villavicencio-Chávez, Tomás-Sábado, & Balaguer, 2011). Methodological inconsistencies and conflicting findings in the research present barriers in developing such a framework. These issues and barriers may result from the challenges in studying this vulnerable population. Due to the physical and

cognitive impact of terminal illness, a large proportion of study populations have not been eligible for participation. Others, who initially enrolled and intended to participate, subsequently needed to withdraw due to symptom issues, disease progression, or death (Achille, 2003; Chochinov et al., 1995; Chochinov et al., 2002; Emanuel, Fairclough, & Emanuel, 2000; George, 2002; Kolva, Rosenfeld, Pessin, Breitbart, & Brescia, 2011; Wilson et al., 2014). Poor patient prognoses have required many studies to employ cross-sectional designs, which hinder researchers' abilities to establish causal relationships (George, 2002; Kelly et al., 2003). Two studies have introduced scales that attempt to measure acuity, the Desire for Death Rating Scale (DDRS), and the Schedule of Attitudes Towards Hastened Death (SAHD) (Chochinov et al., 1995; Rosenfeld et al., 1999). Though the SAHD has been proven more reliable and employed more frequently in the research studies, neither scale has been adopted as a standard measure in the study of hastened death.

Qualitative reports have also generated recommendations that offer more conceptual specificity. A 2006 study designated six "mind frames" toward dying on a continuum, beginning with "neither ready nor accepting," and ending with "considering hastened death with a specific plan" (Schroepfer, 2006). A later study offered a three-category framework to differentiate the nature of one's "desire to hasten death." These constructs were identified as a hypothetical exit plan, an expression of despair, or a manifestation of letting go (Nissim, Gagliese, & Rodin, 2009). The recent literature also provides an "international consensus definition of the wish to hasten death" (Balaguer et al., 2016). This definition characterizes the "desire to hasten death" as a reaction to suffering in the context of terminal illness. The international framework distinguishes the

acceptance of dying, and the wish for death to come soon as conceptually distinct from the “desire for hastened death.” However, this definition was published in January of 2016 and has yet to see recognition in the research on hastened death. Despite the importance of these contributions in understanding the “desire to hasten death,” none have been consistently integrated into the general research and conceptual understanding of this issue. Since the research specific to hospice patients is extremely limited, this study will review a broader scope of literature on hastened death.

### **3.2 Significant Studies: Prospective Research**

#### **Prospective Research with Patients**

In what is widely cited as the first study explicitly exploring terminally ill persons and their “desire to hasten death,” Brown and colleagues explored whether such a desire may be normal in this population (Brown, Henteleff, Barakat, & Rowe, 1986). The researchers used in-person interviews with 44 subjects admitted to an inpatient palliative care service. They administered the short-form version of the Beck Depression Inventory, as well as a checklist that might indicate whether patients were suffering from affective disorders as outlined in the DSM-III. Of the 44 participants, 10 described a desire to die. The researchers found a direct correlation between depression and a desire for death, with each of the ten respondents who wanted to die also meeting criteria for depression. This study was limited in sample size, but significant in its early focus on this issue. One important conclusion the researchers drew was that the criteria for depression may require modification when studying a terminally ill population, as many effects of terminal illness mirror those of depression.



The next ten years saw significant changes in the scope of hospice care, and, with the expansion of services, interest and research in end-of-life issues grew. Through the 1993 expansion of the Medicare benefit and ensuing alterations in funding and reimbursement rates, hospice care became accepted medical practice, and a large-scale expansion of hospice programs and services followed. These developments inspired widespread re-examination of ethics at end of life care and changes in the approach to terminal illness.

Though this review primarily focuses on research within the United States, a number of Canadian studies have offered important findings and direction within this body of research. The U.S. and Canada have seen similarly active debate about right to die issues, and death with dignity has been legalized in certain jurisdictions in each country. For these reasons, Canadian research is included in this discussion.

The mid 1990's introduced several larger-scale research studies exploring the "desire for hastened death." In 1995, a Canadian study interviewed 200 patients in hospital palliative care units (Chochinov et al., 1995). Researchers used semi-structured diagnostic interviews, administered by psychiatric nurses, to assess a patient's desire for death. These interviews were focused on diagnosing depression, but included a section asking if a patient had ever wished for his or her disease to progress more quickly and cause death soon. If a patient said yes, researchers asked a series of follow up questions designed to clarify the intensity of the patient's wish to die. The interviewers rated patient responses on a seven-point scale: (0) no information, (1) no desire, (2) slight desire, (3) mild desire, (4) moderate desire, (5) strong desire and (6) extreme desire. This, the *Desire-for-Death Rating Scale* (DDRS), was the first tool designed specifically to assess

the “desire to hasten death” among terminal patients. The DDRS has been replicated and shown to lack reliability (O'Mahony et al., 2005). Other researchers have employed a modified version of the scale with more consistent results (Kelly et al., 2003; Wilson et al., 2014).

The research team also evaluated pain, social support, functional limitation, and administered a standard depression scale (Chochinov et al., 1995). This was the first exploration of the impact that factors other than depression might have on the “desire to hasten death.” Results highlighted a new finding in determining that, unlike Brown’s (1986) research, patients who wished to die were not all suffering from depression. This study also established positive correlations with both severity of pain and low social support and the degree of one’s “desire to hasten death.” Results indicated that 45% of respondents expressed a more fleeting, passive desire to die soon, while 8.5% of participants scored either 5 or 6 on the DDRS, indicating an active, pervasive wish to hasten death (Chochinov et al., 1995).

Follow-up interviews in this study revealed another important finding, where several participants who had originally met criteria as desiring hastened death, did not meet criteria in follow-up, indicating that one’s “desire to hasten death” may change over time. This is the first major study published by Chochinov and colleagues, who have continued research into this issue (Chochinov et al., 2006; Chochinov et al., 2002; Chochinov et al., 2008; Chochinov et al., 2011; Chochinov et al., 2012; McPherson, Wilson, & Murray, 2007; McPherson, Wilson, Chyurlia, & Leclerc, 2010; Wilson et al., 2014; Wilson, Curran, & McPherson, 2005; Wilson et al., 2007; Wilson, Kowal, Henderson, McWilliams, & Péloquin, 2013).

This time period also saw the publication of a larger scale American study on illness and “hastened death,” with a focus on HIV patients (Breitbart, Rosenfeld, & Passik, 1996). Though this study focused on a population with chronic rather than terminal illness, it is widely cited as one of the foundational studies on “the desire to hasten death.” Researchers explored interest in physician-assisted suicide (PAS) in a group of 378 ambulatory HIV patients. They used a number of self-report questionnaires to assess many of the same issues that Chochinov and colleagues (1995) had measured, with the addition of a hopelessness scale. Fifty-five percent of respondents reported that they would consider PAS as an option for themselves. This research showed that an interest in PAS positively correlated with depression, hopelessness and Caucasian race, and negatively correlated with religious attendance and social support. Investigators also determined that, while a connection between depression and desire for PAS was present, it was not the primary factor. This study did not find a correlation between interest in PAS and pain and symptom distress, or decline in physical functioning.

This cohort of researchers was later responsible for development of the *Schedule of Attitudes Towards Hastened Death* (SAHD) (Rosenfeld et al., 2000; Rosenfeld et al., 1999). This 20-point true/false was designed to address some of the limitations identified with Chochinov’s DDRS (Chochinov et al., 1995) and offers increased precision in quantifying the quality of a respondent’s “desire to hasten death.” Several studies on hastened death have included the SAHD, and supported the reliability and validity (Albert et al., 2005; Jones, Huggins, Rydall, & Rodin, 2003; Ransom, Sacco, Weitzner, Azzarello, & McMillan, 2006; Rodin et al., 2007).

Research within an ambulatory HIV population may have limited generalizability to a home hospice population, especially considering issues such as functional status, care needs, and prognosis. However, contributors to this study have continued their research with a focus on patient populations that are seriously or terminally ill (Abbey, Rosenfeld, Pessin, & Breitbart, 2006; Breitbart, Gibson, Poppito, & Berg, 2004; O'Mahony et al., 2005; Pessin et al., 2008; Pessin, Rosenfeld, & Breitbart, 2002; Rosenfeld et al., 1999; Rosenfeld et al., 2006; Rosenfeld et al., 2014). These later studies have supported Breitbart's (1996) initial findings, indicating positive correlations with depression and hopelessness, and a negative correlation with religion and social support. There were notable exceptions in the outcomes related to pain and physical functioning. The original study did not show these factors to be correlates, while this group's later research has identified a positive correlation between pain and the "desire for hastened death" (Rosenfeld et al., 2000; Rosenfeld et al., 2006).

Another significant early contribution to the study of the "desire for hastened death" explored patient and caregiver perspectives on physician-assisted suicide (PAS) among subjects diagnosed with amyotrophic lateral sclerosis (ALS) (Ganzini, Johnston, McFarland, Tolle, & Lee, 1998). This Oregon based-study was inspired by the passage of the Death with Dignity Act in that state. Though the law had been passed, PAS was not yet accessible to state residents. Researchers interviewed one hundred ALS patients in Oregon and Washington with a six-month or less prognosis. This study is one of the first to include feedback from patients at home, where 98% of respondents were interviewed. They also noted that 20 participants were receiving hospice care. Due to the functional limitations of this population, researchers modified their instruments to a yes/no format

so that patients with a limited ability to communicate would be able to participate. This study assessed the correlation between participant interest in PAS and factors such as social support, hopelessness, depression, functioning, symptom issues and perceived caregiver burden. Fifty-six percent of patients reported that they would consider PAS as an option for themselves and 44% said that they would request a lethal prescription were it available. Results showed hopelessness, religion, and socioeconomic factors were statistically significant indicators of patient interest in PAS. Researchers did not find a causal relationship between depression, social support, functional decline, or pain and a patient's interest in pursuing PAS.

Another large-scale study investigated terminally ill patient and caregiver attitudes towards euthanasia and physician-assisted suicide (PAS) (Emanuel, Fairclough, & Emanuel, 2000). This study included 988 terminally ill patients in six randomly selected areas, as well as 893 primary caregivers of terminally ill patients. Patient participants were interviewed using a 135-item survey that assessed opinions on PAS through discussion of hypothetical scenarios. Researchers also conducted 650 in-person interviews 2-6 months after the initial encounter. Sixty percent of survey respondents reported support for PAS, and 13.7% had seriously considered or requested PAS for themselves. Consistent with Chochinov's (1995) findings, results indicated that interest in PAS was not consistent, and may change over time. The researchers found that depression, significant care needs, and pain impacted one's desire to die. In this study, investigators did not identify where patients were receiving care, and therefore it is not possible to understand how well it might represent the home hospice population.

Additional prospective studies have continued to gather data from patients themselves. The majority of these studies have used quantitative methods. A 2004 study that consisted almost entirely of home care patients (98.6%) used mailed surveys to collect data on the consideration of hastening death among 148 respondents with life threatening illnesses (Arnold, Artin, Person, & Griffith, 2004). This study identified depression, degree of social support and hope as the most significant factors. A New York City-based study used scales to measure the “desire for hastened death” in 80 end-stage ALS patients (Albert et al., 2005). This study found a positive correlation with hopelessness and a negative correlation with religiosity. Researchers interviewed patients in their homes and one nursing home. The findings described home hospice patients within the study sample, but did not clarify the number of hospice participants. In a 2009 Oregon survey of 56 persons who inquired about physician-assisted suicide, respondents included 53 home-based patients, 20 of whom were enrolled in hospice (Ganzini, Goy, & Dobscha, 2009). This study inquired about reasons patients made these requests and found that current symptom issues were rated as low in importance, but concern about future pain was a primary concern. Other issues that rated highly were control, fear of being a burden, and a wish to die at home.

By contrast, there are fewer prospective patient-focused studies that have used qualitative methods. A Canadian study used qualitative interviews to explore views on PAS among 32 patients with HIV-1 and AIDS (Lavery, Boyle, Dickens, Maclean, & Singer, 2001). Findings indicated that the most significant factors were perceived burden, witnessing others die of AIDS, declining functioning and social isolation on the “desire to hasten death.” Another large Canadian study interviewed 379 patients about their desire

for euthanasia or PAS (Wilson et al., 2007). The researchers recruited participants from inpatient palliative care units, hospices, hospitals, and home care settings. Findings showed interest in PAS to be most strongly affected by weakness, suffering, autonomy, perceived burden, and lower religiosity. This study also included seventeen follow-up interviews with patients who expressed interest in PAS and found that two respondents were inconsistent in their wish to hasten death.

Schroepfer's (2007) exploration of the potential for suffering in the dying process is an important contribution to this body of research, and has been widely referenced by researchers from all disciplines. This qualitative study was comprised of 96 terminally ill individuals who were receiving care at home, outpatient hospital services, or inpatient settings. The researcher sought to move beyond the causal factors that had been previously identified, and explore what events during the course of a patient's illness might contribute to his or her suffering. The study identified four such events: (1) insensitive communication related to diagnosis, (2) unbearable pain, (3) feeling that trauma of treatment was unacknowledged by one's support system, and (4) dying in a distressing environment. Through identifying these critical events, this study offers insight regarding potential stressors that can help guide clinical practice. This research is significant to the body of literature on "hastened death" because it uses qualitative methods to offer a more in-depth and clinically significant perspective and initiates a shift towards consideration of social work interventions.

## **Prospective Research with Clinicians**

In the early and mid 90's, the discussion of physician-assisted death (PAD) transitioned from theory to law with the 1994 passage of Oregon's Death with Dignity Act (Oregon Health Authority, 2013). After several challenges, this ballot measure was enacted in 1997, thereby legalizing PAD in the state of Oregon. With this momentous change in US healthcare policy, studies began to explore practitioner perspectives on PAD. Research on PAD is very relevant in the study of the "desire for hastened death" because the law was enacted so terminally ill patients who wish to die have the right to pursue that option.

One of the earlier practitioner-focused studies surveyed 938 physicians in Washington State on their attitudes towards PAS and euthanasia (Cohen, Fihn, Boyko, Jonsen, & Wood, 1994). This review will focus on PAS only, as euthanasia is more complex and less relevant because it may not be initiated by the patient. A mailed survey found 53% of respondents believed that PAS should be legal in some situations. Of the PAS supporters, 97% cited a patient's right to self determination, and 91% believed that access to PAS may result in some reduction of patient fears of loss of control or pain. Among the physicians who supported PAS, 88% felt that poor quality of life could justify PAS and 31% felt that even if patient quality of life is currently good, PAS might still be appropriate if their illness is expected to cause severe mental and/or physical deterioration.

By 1996, Oregon's Death with Dignity Act had passed, but PAS was not yet legal. Following Cohen's (1994) findings, researchers in Oregon looked specifically at psychiatrists' views on PAS in that state (Ganzini, Fenn, Lee, Heintz, & Bloom, 1996). In



this mailed survey, 68% of respondents agreed that PAS would be morally acceptable in circumstances such as terminal illness. One compelling discovery in this research is the personal data, where 74% of the psychiatrists reported that they would consider PAS for themselves if terminally ill. This disparity highlights some of the ethical ambiguity regarding end of life issues. Practitioners struggle to find balance between their personal beliefs and what they view as their professional responsibility (Csikai, 1999). This study provided additional insight through an open-ended section that asked respondents to discuss conditions that might lead them to seek PAS. Pain and terminal illness were the most frequently cited reasons, followed by self-care deficit, poor quality of life, mental incapacity, insufficient finances, and burdening others. This data provides insight into physician perspectives as to why one might wish to hasten death. This is notable because many studies are initiated by physicians, whose beliefs and experiences inform their study designs and measures. Though these two early studies (Cohen, Fihn, Boyko, Jonsen, & Wood, 1994; Ganzini, Fenn, Lee, Heintz, & Bloom, 1996) had significant response rates, they were both conducted in the Pacific Northwest, with limited generalizability.

A 1997 study explored practitioner perspectives on PAS in New York City (Portenoy et al., 1997). This study is notable for its inclusion of nurses and social workers, as well as physicians. Researchers used a mailed survey to capture clinician willingness to endorse PAS. Findings showed social workers as significantly more willing to endorse PAS than nurses or physicians. This study included data on clinician religion, and concluded that both religiosity of the practitioner, and the religion itself

were significant. In this sample, Catholic clinicians were least likely to support PAS, while Jewish clinicians were most likely to support PAS.

After the legalization of PAD in Oregon, researchers saw an opportunity to explore hastened death as a legal and acceptable option, and gather data about patients who choose to hasten death. A 2004 study investigated hospice social work and nursing experiences with PAS (Miller et al., 2004). The study sample consisted of 309 nurses and 85 social workers representing home, inpatient, and prison hospice settings. Over 60% of participants reported caring for at least one patient who had considered pursuing PAS within the past year. This study also found social workers (72%) to be more supportive of PAS than nurses (48%) or physicians (51%). In addition, social workers reported higher comfort levels than nurses in speaking to patients about PAS.

### **3.3 Significant Studies: Retrospective Research**

#### **Retrospective Research with Families**

Given the sensitivity of the subject, vague conceptualization, and limited legality of “hastened death,” several researchers have used a retrospective approach in their inquiry. Retrospective research with family proxies has been reported to have mixed accuracy, where certain areas are more reliable than others. The more reliable areas are observable, often physical, issues such as shortness of breath, while less reliable areas include less observable factors such as mood (McPherson & Addington-Hall, 2003). One retrospective study surveyed 83 family members of Oregonians who had chosen to pursue a hastened death (Ganzini, Silveira, & Johnston, 2002). Family members cited control, loss of independence, fear of burdening loved ones, and the desire to die at home as primary factors in these decisions. Factors such as depression, social support, and

financial concerns were reported to be of much lower importance. Patient care setting was not described in this study.

A more recent retrospective study used an in-person survey to explore differences in quality of dying among patients who requested and received, requested and were not eligible or did not pursue, or never requested physician-assisted death (PAD) (Smith, Goy, Harvath, & Ganzini, 2011). Researchers surveyed 147 family members of deceased patients in Oregon. Responses revealed that patients who received PAD were characterized as having more control over their surroundings. This study determined that quality of life was not a factor in the decision to hasten death. The data analysis provided evidence that patients who had received PAD were more likely to feel in control and to have higher functional ability than the other groups. Another notable finding was that the group that requested, but did not receive PAD, appeared more concerned with burdening loved ones. Researchers concluded that pursuit of PAD did not appear correlated to poor symptom management or lack of quality end of life care.

### **Retrospective Research with Clinicians**

A Washington state-based survey asked 828 physicians about their experiences with PAS and euthanasia (Back, Wallace, Starks, & Pearlman, 1996). The study yielded 207 case descriptions about patients who inquired about or pursued hastened death through PAS or euthanasia. The study also included ten qualitative interviews by phone to explore these issues more deeply. As perceived by physicians, factors related to the “desire for hastened death” included control, perceived burden, loss of dependence, functional decline, depression, and physical suffering. The study also noted that

physicians were more likely to aid in dying when physical suffering was the primary factor, and were less comfortable assessing psychological suffering.

In 1998, the first large national study of PAS was published (Meier et al., 1998). Researchers surveyed 1902 physicians about their beliefs and experiences with PAS and Euthanasia. This study examined physician experiences with requests for PAS and their willingness to comply. Among the physicians who participated in this study, 3.3% acknowledged providing a lethal prescription and 4.7% had given lethal injections. This data illustrates the gravity of this issue and a belief in PAS that feels so compelling to some physicians that they were willing to illegally aid their patients in dying. The study also provided physician perspectives on reasons patients requested PAS. These included pain and other discomfort, loss of dignity, fear of symptoms, loss of life meaning, being a burden, and dependency. In this survey, men made 97% of requests. The criteria that physicians cited as influencing decisions to comply with requests for PAS included pain and other discomfort, intractable symptoms, and poor prognosis.

Given the imperative of anonymity when evaluating clinician experiences and involvement with PAD, the majority of such studies appear to use the mailed survey as the method. This was true in an Oregon-based study that explored the experiences with PAS among 397 hospice nurses and social workers (Ganzini et al., 2002). All participants were working in home-based hospice settings. Clinicians were asked to rank the importance of 21 reasons that their patients had considered requesting aid in dying. The reasons ranked most significant were (1) desire to control circumstances surrounding death, (2) readiness for death, and (3) desire to die at home. The factors these clinicians rated least important were depression, financial concern, and lack of social support.

Another smaller study explored hospice social worker experiences with the “desire for hastened death” (Arnold et al., 2004). Data was collected via mailed surveys to 73 respondents who worked at hospices in the Southeastern United States. This sample included both community-based and inpatient social workers. Among the respondents, 56% reported having cared for patients who expressed a “desire to hasten death.” The survey also included an open-ended section where social workers discussed what they perceived to be the reasons behind these requests. The list of reasons was comprehensive, but the most common were: ‘decreased ability to participate in activities that make life enjoyable,’ ‘poor perceived quality of life,’ ‘loss of autonomy,’ ‘depression,’ and ‘fear of being a burden to others.’ The scope of this study is limited, but noteworthy in its inclusion of social work observations, as well as the data collected on factors related to one’s “desire to hasten death.”

### **Retrospective Research: Oregon’s Statistics**

In 1998, 23 terminally ill individuals were the first in the United States to receive legal prescriptions to end their lives. A 1999 analysis of the data on Oregon’s first year of legal PAD compared these patients to a case-control sample of terminally ill Oregonians with similar prognoses and characteristics (Chin, Hedberg, Higginson, & Fleming, 1999). The study noted that 80% of patients who received PAD died at home. They differed from the control group in higher concern about loss of autonomy and loss of control of bodily functions. Findings also highlighted a social aspect, and case patients were more likely to have never married or have been divorced. Researchers did not identify significant difference in demographics, symptom management, or financial concerns.

Since the legalization of Oregon's Death with Dignity Act, the Oregon Health Authority has been collecting data on the patients who are provided lethal prescriptions. The 2013 report provides a wealth of information about the individuals who pursued physician aid in dying (Oregon Department of Human Services: Oregon Public Health Division, 2014). In that year, 122 patients received lethal prescriptions, and 71 used those prescriptions to end their lives. The primary reasons patients reported for their pursuing PAS were (1) loss of autonomy (2) loss of ability to participate in meaningful activities, and (3) loss of dignity. These patients were 94.4% Caucasian and 85.7% were enrolled in hospice programs. Death occurred at home in 97.2 cases. Patients were also well educated, with 83.1% listing education as some college or greater. The report also looked at historical numbers and noted that 2013 was similar in these areas to previous years.

### **3.4 Significant Studies: Prospective and Retrospective Research**

An important contribution to the research on hastened death focused on a group of study subjects that included both those who were currently pursuing Physician Assisted Suicide (PAS) (N=12) and family members of patients who had already hastened their deaths (N=23). Researchers used qualitative methods in conducting 159 interviews with patients and family members to seek a deeper understanding of the "desire to hasten death" (Back et al., 2002; Bharucha et al., 2003; Pearlman et al., 2005; Starks et al., 2005). These interviews led to a series of publications about the characteristics and concerns among study subjects. The setting was described as "community-based," but does not clarify the number of patients enrolled in home hospice care. Primary factors in these were patient desire for control, fear of future suffering, rational choice, and

comorbid psychiatric factors. Researchers found that depression was not reported to be a primary factor among these respondents.

### **3.5: Research Considerations**

It is important to consider the impact of these varying approaches to studying the “desire for hastened death.” Research is both prospective and retrospective, and study populations have included patients, families, and clinicians. Studies evaluate a broad range of factors using different measures and controlling for different variables. This wide range of research designs may limit the consistency of the findings in the literature on the “desire to hasten death.”

## **Chapter 4: Previous Research into Factors Contributing to the Desire for Hastened Death**

Research into “hastened death” has revealed a broad range of factors that have been linked to the “desire for hastened death.” This review will focus on some of those most frequently addressed in the literature, including the following: depression and hopelessness, social support, perceived burden, physical distress, anxiety, functional decline, spirituality, coping, and rational choice. Given this paper’s aim of enhancing understanding of the “desire for hastened death” in the home hospice environment, factors will be considered in within this context. Several studies discuss the concepts of quality of life and suffering in relation to “hastened death” (Breitbart et al., 2012; Breitbart et al., 2015; Krikorian, Limonero, & Maté, 2012; Stewart, Teno, Patrick, & Lynn, 1999). However, these concepts are too general to analyze in this context. Dignity is another construct that is often connected to end of life issues, and there has been some

exploration into its impact on the “desire to hasten death” (Block & Billings, 1994; Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002; Chochinov et al., 2006; Chochinov et al., 2002; Chochinov et al., 2008; Ganzini et al., 2002; Ganzini, Silveira, & Johnston, 2002; Oregon Health Authority, 2013). However, like quality of life, dignity is identified as a broad, multidimensional concept that incorporates physical, psychological, social, and existential domains (Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002; Chochinov et al., 2006). Given the breadth of these concepts, dignity and quality of life may confound the study of other factors, and thus, will not be included in this review.

#### **4.1 Contributing Factors: Psychological Distress**

##### **Depression**

Depression is the most widely researched factor in the study of hastened death. Despite such prevalence in the research, findings remain inconsistent. As Brown (1986) observed in his early study, many effects of terminal illness may mirror criteria for depression. Research that followed has attempted to address this issue through modifying scales to eliminate items that may reflect effects of illness (Chochinov et al., 1995; Emanuel, Fairclough, & Emanuel, 2000; Pessin, Rosenfeld, & Breitbart, 2002). With or without these modifications, study outcomes remain inconsistent. The majority of studies show a significant positive correlation between depression and the “desire to hasten death” (Anguiano, Mayer, Piven, & Rosenstein, 2012; Arnold, 2004; Back, Wallace, Starks, & Pearlman, 1996; Breitbart et al., 2000; Chochinov et al., 1995; Emanuel, Fairclough, & Emanuel, 2000; Kelly et al., 2003; O'Mahony et al., 2005; Rodin et al., 2007; Rosenfeld et al., 1999; Rosenfeld et al., 2006; Wilson et al., 2014; Wilson et al., 2007). However, there are also a number of studies that contradict these findings and



report no significant depression correlation (Albert et al., 2005; Bharucha et al., 2003; Cohen, Dobscha, Hails, Pekow, & Chochinov, 2002; Ganzini, Johnston, McFarland, Tolle, & Lee, 1998; Ganzini & Dobscha, 2003; Pearlman et al., 2005; Starks et al., 2005). These mixed outcomes highlight the challenge of assessing depression in a terminally ill population. In addition to the similar characteristics seen in both depression and illness, assessment may be further complicated by the effects of high doses of medications and the increased risk of organic mental disorders (Block & Billings, 1994). The varied outcomes in the study of depression may indicate a need to develop a scale more specific to terminal illness.

It is difficult to predict how the influence of depression would differ in the homecare environment. One concern is that without the constant monitoring and medication administration one sees in a facility setting, patients may not be relied upon to take medications for depression as prescribed. This may not be evident to hospice clinicians due to their limited ability to oversee daily medication management, so treatment of a patient's depression may not be as reliable as in an inpatient scenario.

### **Anxiety**

Concern about effective medical management may also be relevant in addressing patient anxiety, which is common in a hospice population (Block & Billings, 1994; Block, 2001; Pessin, Rosenfeld, & Breitbart, 2002). Anxiety is frequently indicated in the literature as contributing to the "desire for hastened death" (Ganzini, Goy, & Dobscha, 2008; Kelly et al., 2003; Kolva, Rosenfeld, Pessin, Breitbart, & Brescia, 2011; Pessin, Rosenfeld, & Breitbart, 2002; Renz, Mao, Bueche, Cerny, & Strasser, 2013). Despite the continued assessment of anxiety among terminally ill patients, the concept remains

unclear (Kolva, Rosenfeld, Pessin, Breitbart, & Brescia, 2011; Pessin, Rosenfeld, & Breitbart, 2002). Some researchers characterize anxiety as manifest in fears of dying (Block & Billings, 1994; Krikorian, Limonero, & Maté, 2012). Others discuss the anxiety response to stresses and symptoms related to illness (Kolva, Rosenfeld, Pessin, Breitbart, & Brescia, 2011; Rosenfeld, 2000). The majority of studies grouped anxiety scales in with measurements for other psychological disorders and provided only brief mentions of outcomes related to anxiety (Costantini et al., 2014; Ganzini, Goy, & Dobscha, 2008; Kelly et al., 2003; Mystakidou et al., 2005; Wilson et al., 2014; Wilson et al., 2007). This approach to data collection on anxiety is problematic due to commonalities in the presentation of anxiety, depression and delirium (Block & Billings, 1994; Block, 2001; Kolva, Rosenfeld, Pessin, Breitbart, & Brescia, 2011; Pessin et al., 2008). Research that specifically focuses on anxiety in the context of terminal illness is extremely limited (Kolva, Rosenfeld, Pessin, Breitbart, & Brescia, 2011; Pessin et al., 2008; Rosenfeld, 2000). One possibility may be that this gap in the literature is due to the absence of an operational understanding of anxiety in the context of end of life. This presents an important opportunity to develop a clearer operational understanding of this issue through qualitative inquiry.

Anxiety at home may differ from the inpatient experience for several reasons. One, again, relates to medication management and appropriately managing symptoms. The inpatient setting may be anxiety provoking, being an unfamiliar environment for patients where they may have a number of strangers visiting their room and asking uncomfortable questions. Hospital patients may feel nervous about medical testing and interventions. In hospitals and inpatient hospice facilities, patients may feel isolated from

loved ones. Conversely, home may provide a more comforting, familiar environment, but the home hospice setting does not provide the reassurance of having staff available at all times to address illness-related issues. Though hospices offer 24-hour support by phone and visits if needed, not having medical professionals present at all times could prove anxiety-provoking to home hospice patients. It will be important to learn more about anxiety in this population and the significance of this factor in one's "desire to hasten death."

### **Hopelessness**

One response to the challenges in measuring depression and anxiety has been an increased focus on hopelessness, which some researchers are exploring as a significant and, possibly, more accurate indication of a terminal patient's quality of life (Abbey, Rosenfeld, Pessin, & Breitbart, 2006; Anguiano, Mayer, Piven, & Rosenstein, 2012; Breitbart et al., 2000; Rosenfeld et al., 2011; Sachs, Kolva, Pessin, Rosenfeld, & Breitbart, 2013). One key study showed hopelessness to be 1.3 times more accurate than depression in predicting suicidal ideation (Beck, Weissman, Lester, & Trexler, 1974). Originally considered a symptom of depression, more recent interpretations have classified hopelessness as a distinct psychological indicator (Abbey, Rosenfeld, Pessin, & Breitbart, 2006). Sullivan (2003) described hopelessness as "attachment to a form of hope that is lost" (p. 393). Hopelessness has been linked to the "desire for hastened death" in numerous studies (Abbey, Rosenfeld, Pessin, & Breitbart, 2006; Achille, 2003; Albert et al., 2005; Block & Billings, 1994; Jones, Huggins, Rydall, & Rodin, 2003; Kelly et al., 2003; Rodin et al., 2007; Rosenfeld et al., 2011; Rosenfeld et al., 2006; Sullivan, 2003; Wilson et al., 2007). The demonstrated correlation between hopelessness and "the desire

for hastened death” has been so compelling that researchers have developed an assessment tool specifically for use with a terminally ill population (Rosenfeld et al., 2011). *The Hopelessness Assessment in Illness Questionnaire* (HAI) was developed as an 8-item scale that asks respondents to select one of three anchored statements such as, “(0) I have nothing to look forward to. (1) I am looking forward to some things. (2) I am looking forward to many things” (Rosenfeld et al., 2011).

It is unclear whether the nature of hopelessness would differ in the home hospice setting. There is a possibility that, for some patients, dissatisfaction with their environment may increase a sense of hopelessness, but this would vary for each patient based on his or her environment.

### **Psychiatric History**

Presence of a psychiatric history has also been consistently found to increase the probability that a terminally ill person will “desire to hasten death” (Bharucha et al., 2003; Block & Billings, 1994; Fairman, Morrison, Ligon, Nelesen, & Irwin, 2012; Krikorian, Limonero, & Maté, 2012; Miller, Hedlund, & Murphy, 1998; Owen, Tennant, Levi, & Jones, 1994; Rosenfeld et al., 1999; Wilson et al., 2014). Prevalence of the wish to hasten death has been shown to have a high correlation with both former and current diagnoses of mental illness. As a historical factor, a hospice patient’s current environment is unlikely to alter the impact a previous psychiatric condition may have on one’s “desire to hasten death.”

## **4.2 Contributing Factors: Physical Distress**

### **Pain and Symptoms**

Pain and other symptom-related discomfort, such as shortness of breath and swelling, has generally been expected to have a positive correlation with the “desire for hastened death.” In surveys of physicians, symptom issues were cited as a primary reason to pursue PAD (Back, Wallace, Starks, & Pearlman, 1996; Cohen, Fihn, Boyko, Jonsen, & Wood, 1994; Ganzini, Fenn, Lee, Heintz, & Bloom, 1996; Meier et al., 1998). The majority of studies did corroborate these findings (Albert et al., 2005; Block & Billings, 1994; Breitbart et al., 2000; Chochinov et al., 1995; Jones, Huggins, Rydall, & Rodin, 2003; Kelly et al., 2003; Monforte-Royo, Villavicencio-Chávez, Tomás-Sábado, & Balaguer, 2011; Nissim, Gagliese, & Rodin, 2009; Pearlman et al., 2005; Raue, Meyers, Rowe, Heo, & Bruce, 2007; Rodin et al., 2007; Rosenfeld et al., 1999; Starks et al., 2005; Wilson et al., 2007; Wilson, Kowal, Henderson, McWilliams, & Pélouin, 2013). However, there remains empirical inconsistency as evidenced by a smaller group of studies that did not find any significant correlation between physical symptoms and “the desire to hasten death” (Arnold, 2004; Breitbart, Rosenfeld, & Passik, 1996; Breitbart et al., 2000; Chin, Hedberg, Higginson, & Fleming, 1999; Ganzini, Goy, & Dobscha, 2009). Another study concurred with a symptom correlation, but showed that the impact of this factor was considerably lower than that of psychological or social factors (Kelly et al., 2003).

There is more agreement in the research findings that evaluated a patient’s fear of future pain and suffering. Several studies found this to be highly correlated to the “desire to hasten death” (Ganzini et al., 2002; Miller, Mesler, & Eggman, 2002; Pearlman et al.,

2005; Starks et al., 2005). Another way this fear of future suffering has been captured is through exploring a patient's previous experience with dying. Studies found that those who had previously witnessed death, especially a negative dying experience, were more likely to "desire a hastened death" (Ganzini, Goy, & Dobscha, 2009; Lavery, Boyle, Dickens, Maclean, & Singer, 2001; Pearlman et al., 2005; Wilson et al., 2007).

The home hospice model depends on lay caregivers to manage all patient care needs. These informal caregivers are usually inexperienced, and frequently express discomfort in the administration of narcotic medications. This has resulted in less effective symptom management, as compared to inpatients treated by medical professionals (Letizia, Creech, Norton, Shanahan, & Hedges, 2004; McMillan & Small, 2007). Therefore, there is a possibility that physical suffering may be a more significant factor in a home hospice setting than in an inpatient setting.

### **Functional Decline**

Functional decline is another important indicator of one's "desire for hastened death." As one's illness progresses, that patient becomes weaker, more fatigued, and loses ability to function physically. This results in increased dependence on assistance from others, and decreased ability to participate in one's usual activities. Studies have seen consensus in identifying a positive correlation between the extent of a patient's functional decline and the intensity of that individual's "desire to hasten death" (Arnold, Artin, Person, & Griffith, 2004; Arnold, 2004; Breitbart et al., 2000; Chin, Hedberg, Higginson, & Fleming, 1999; Cohen, Fihn, Boyko, Jonsen, & Wood, 1994; Lavery, Boyle, Dickens, Maclean, & Singer, 2001; Oregon Health Authority, 2013; Pearlman et al., 2005; Rodin et al., 2007; Wilson et al., 2007). The significance of functional decline

may also be influenced by the care setting, and it is important to have a better understanding of its impact among home hospice patients. For example, if patients are unable to continue with routines and aspects of household management that they have mastered throughout their lives, being in one's home might increase awareness of physical losses, which could exacerbate distress related to functional decline.

### **4.3 Contributing Factors: Interpersonal Distress**

#### **Social Support**

Several studies have shown a negative correlation between quality of social support and the “desire for hastened death” (Achille, 2003; Applebaum et al., 2014; Block & Billings, 1994; Breitbart, Rosenfeld, & Passik, 1996; Breitbart et al., 2000; Kelly et al., 2003; Ransom, Sacco, Weitzner, Azzarello, & McMillan, 2006; Raue, Meyers, Rowe, Heo, & Bruce, 2007; Rowe, Conwell, Schulberg, & Bruce, 2006; Schroepfer, 2006; Schroepfer, 2007; Schroepfer, 2008; Schroepfer & Noh, 2010; Wilson, Curran, & McPherson, 2005). It is logical to expect that a patient would benefit from the support of a robust social network, both emotionally, and in terms of having personal needs met. However, the home environment may add complexity in understanding a patient's relationship to his or her support network. In the hospital, that network may provide support through friendly visits and healthcare advocacy, while at home, the patient's network necessarily transitions from social to caregiving. Within the context of this new dynamic, hospice patients express feelings of guilt because their conditions require so much time and energy from those around them (McPherson, Wilson, & Murray, 2007).

## **Self-Perceived Burden**

The literature refers to these feelings of guilt as “self-perceived burden” and it is also positively correlated with the “desire for hastened death” (Block & Billings, 1994; Breitbart, Rosenfeld, & Passik, 1996; Kelly et al., 2003; Krikorian, Limonero, & Maté, 2012; McPherson, Wilson, & Murray, 2007; McPherson, Wilson, Chyurlia, & Leclerc, 2010; Ransom, Sacco, Weitzner, Azzarello, & McMillan, 2006; Schroepfer, 2008; Schroepfer & Noh, 2010; Van Loon, 1999; Wilson et al., 2007). The majority of end of life research has taken place within the context of institutional settings for reasons related to efficiency of access to study subjects (Rosenfeld, 2000b). In an institutional context, the involvement of a patient’s interpersonal network is limited by the presence of hospital staff and setting regulations. At home, depending on a patient’s functional ability and financial resources available to hire help, his or her network is responsible for all day-to-day patient care. In surveys that asked patients to rank importance of factors in their decisions to pursue hastened death, “desire to die at home” was a primary motivation (Ganzini, Goy, & Dobscha, 2009; Ganzini, Silveira, & Johnston, 2002). However, a sense of guilt about burdening caregivers can be so acute that some patients who would otherwise wish to be home, choose facility-based care in order to avoid causing stress to loved ones (McPherson, Wilson, & Murray, 2007). Current literature offers limited information on the influence of these interpersonal factors in the home hospice setting. While some studies do include home-based patients, institutional patients are often evaluated within the same sample; therefore limiting findings specific to the home care setting (Arnold, Artin, Person, & Griffith, 2004; Breitbart, Rosenfeld, & Passik, 1996; Schroepfer, 2008; Wilson et al., 2007). In light of the heightened caregiving challenges



faced in home hospice settings, it is crucial to further explore the impact of social support and perceived burden on the “desire for hastened death” in this unique environment.

#### **4.4 Contributing Factors: Demographics**

##### **Spirituality**

There is consensus in the literature that a stronger sense of spiritual well being is associated with lowered interest in “hastened death.” A spiritual or religious connection may reduce thoughts of hastening death in one of two ways. First, some religions have prohibited these practices. Second, a spiritual connection can facilitate coping and offer an additional source of support and comfort (Albert et al., 2005; Block, 2001; Breitbart, Rosenfeld, & Passik, 1996; Breitbart et al., 2000; Breitbart, Gibson, Poppito, & Berg, 2004; Ganzini, Johnston, McFarland, Tolle, & Lee, 1998; Ransom, Sacco, Weitzner, Azzarello, & McMillan, 2006; Rodin, 2013; Rosenfeld, 2000a; Stewart, Teno, Patrick, & Lynn, 1999; Wilson et al., 2007). Like all of the demographic factors presented, the influence of spirituality on the “desire to hasten death” is not anticipated to vary whether a patient is receiving hospice care at home or in an inpatient setting.

##### **Race**

Caucasian race has frequently been cited as correlated to hastened death (Back et al., 2002; Bharucha et al., 2003; Breitbart, Rosenfeld, & Passik, 1996; Chin, Hedberg, Higginson, & Fleming, 1999; Norton & Miller, 2012; O'Mahony et al., 2005; Oregon Health Authority, 2013). However, because it was the first state to legalize PAD, there are a disproportionate number of studies based in Oregon, a state with a population that is over 88% Caucasian (United States Census Bureau, 2014). Additionally, several studies have included hospice patients, and the hospice population is 81.5% Caucasian (National

Hospice and Palliative Care Organization, 2013). Therefore, it is difficult to draw conclusions from current findings, and this presents an opportunity for further investigation with more diverse populations.

## **Education**

Much of the literature describes a correlation between higher levels of education and “desire to hasten death” (Back et al., 2002; Bharucha et al., 2003; Chin, Hedberg, Higginson, & Fleming, 1999; Lavery, Boyle, Dickens, Maclean, & Singer, 2001; O'Mahony et al., 2005; Oregon Health Authority, 2013; Smith, Goy, Harvath, & Ganzini, 2011). The State of Oregon reported that 83.1% of individuals who chose to end their lives through PAD reported their education level as some college or higher (Oregon Health Authority, 2013). However, there are also some studies that found no significant correlation between level of education and hastened death (Rodin et al., 2007; Rosenfeld et al., 2006).

## **Finances**

Within the debate about death with dignity, financial aspects of legalizing physician-assisted death (PAD) have been a prominent concern. Opponents of PAD have argued that legalization could place terminally ill patients at risk of feeling pressured by managed care. Or, patients' concerns about costs related to treatment and care needs may compel some patients to pursue PAD for financial reasons (Miller, 2000). The literature does not appear to validate this concern, and studies that have inquired about financial stress have found this factor to have minimal impact on a patient's “desire to hasten death” (Ganzini et al., 2002; Ganzini, Silveira, & Johnston, 2002; Lavery, Boyle, Dickens, Maclean, & Singer, 2001; Oregon Health Authority, 2013; Wilson et al., 2007).

Continued research is critical to enhance understanding of the influence of finances on the “desire to hasten death,” and ensure that patients never feel compelled to pursue hastened death due to financial strain.

#### **4.5 Contributing Factors: Coping Mechanisms**

##### **Control and Autonomy**

Several reports have characterized the “desire to hasten death” as a means to cope with the impact of terminal illness (Achille, 2003; Nissim, Gagliese, & Rodin, 2009; Pessin, Rosenfeld, & Breitbart, 2002; Van Loon, 1999). Terminally ill individuals commonly struggle with a loss of a sense of control as their disease progresses (Arnold, Artin, Person, & Griffith, 2004; Back et al., 2002; Block & Billings, 1994; Block, 2001; Ganzini et al., 2002; Krikorian, Limonero, & Maté, 2012; Mesler & Miller, 2000; Miller, Hedlund, & Murphy, 1998; Norton & Miller, 2012; Smith, Goy, Harvath, & Ganzini, 2011; Stewart, Teno, Patrick, & Lynn, 1999; Werth JR, 1995; Werth & Holdwick, 2000; Wilson et al., 2007). Such losses may include a sense of control over one’s physical and cognitive functioning, and, especially the total absence of control over the illness that has been and will continue to be the cause of so many losses. The experience of these losses can result in patients struggling to connect to any sense of autonomy (Arnold, Artin, Person, & Griffith, 2004; Schroepfer, Noh, & Kavanaugh, 2009). These losses have been identified as contributing to emotional and existential suffering, and, in this context, thoughts of hastening death can offer an opportunity to feel in control. The sense of control derived from considering hastened death can actually serve a therapeutic function through offering a patient some sense of self-determination (Achille, 2003; Block &

Billings, 1994; Schroepfer, Noh, & Kavanaugh, 2009; Stewart, Teno, Patrick, & Lynn, 1999).

### **Rational Choice**

The deliberation or decision to hasten death may also be a result of a rational choice to avoid the potential psychological, physical, and existential suffering that many patients anticipate as an illness progresses (Achille, 2003; Block & Billings, 1994; Miller, Hedlund, & Murphy, 1998; Nissim, Gagliese, & Rodin, 2009; Starks et al., 2005; Van Loon, 1999; Werth JR, 1995; Werth & Holdwick, 2000). As the first state to legalize this choice, Oregon has established detailed eligibility criteria designed to ensure that a request to hasten death is not a response to situational factors that may change or improve. Three primary criteria used in assessing rational choice are (1) the absence of cognitive impairment or psychological distress, (2) a deliberate thought process, and (3) an expressed understanding of the interpersonal impact of the decision to pursue PAD (Achille, 2003).

### **Acceptance**

Lastly, the desire to hasten death may be interpreted as an expression of acceptance of one's terminal condition. Acceptance may serve as a means for processing the approaching end of life, or, a communication of preparedness for death (Achille, 2003; Block & Billings, 1994; Block, 2001; Ganzini, Silveira, & Johnston, 2002; Nissim, Gagliese, & Rodin, 2009; Van Loon, 1999; Werth, 1995).

## **Chapter 5: Gaps in the Scientific Literature and Study Aims**

### **5.1 Gaps in the Scientific Literature**

Early literature on hastened death was critical in identifying the significance, prevalence and relevance of this complex issue. This research raised awareness regarding hastened death and emphasized the importance of creating new tools and guidelines designed to address the particular needs in this population. However, there remain numerous opportunities to add meaningful contributions to this literature. There are fundamental issues throughout this body of research. The foundational studies employed quantitative methodology, which raises questions about the relevance of those initial study designs. The study designs were primarily guided by suicide research in a general population, and are unlikely to be generalizable to a terminally ill population. The “desire for hastened death” is distinct from suicide, and cannot be evaluated with the same criteria. In his seminal study, Brown (1986) acknowledged the flaws related to use of a depression measure that did not account for the effect of terminal illness.

As research in this area has expanded, inconsistencies in the findings persist. Such issues may be attributed to the lack of conceptual clarity, confounding factors among variables, or questionable validity of the study scales themselves. Critiques of the state of the literature suggest that a more nuanced conceptual understanding of the desire for hastened death, coupled with more precise measurements, could provide a framework that would generate more accurate and consistent findings (Rosenfeld, 2000b; Schroepfer, 2006).

Rosenfeld (2000b) also calls attention to the absence of studies in home care settings, which he relates to the convenience in accessing inpatient populations. This

analysis emphasizes the need to increase research in home care settings, and posits that a different setting may uncover factors contributing to the “desire for hastened death,” not previously observed among inpatient populations. Another limiting aspect of this research relates to geography. Oregon and Washington were the first two states to legalize physician-assisted death (PAD), which facilitated research on hastened death in those states. This has led to a disproportionate number of studies in this region.

In a review of the international literature, Monforte-Royo and colleagues (2011) identify a need for further qualitative studies. Citing the conceptual ambiguities in defining the “desire to hasten death,” as well as several of the contributing factors, researchers recommend in-depth qualitative inquiry that may offer insight and inform the development of a comprehensive framework. These critiques also emphasize inconsistency in defining contributing factors, as well as inadequacy of instruments that have been adopted for this research. Use of qualitative methods will provide an opportunity to step away from the complexities and inadequacies identified throughout the literature, and focus on developing a deeper and more comprehensive understanding of a patient’s “desire to hasten death.”

## **5.2 Framework for Hastened Death**

Given the absence of conceptual clarity regarding “the desire for hastened death,” this study will explore the full spectrum of such expressions, from passing ideation, to an active desire to die. Past research has outlined numerous factors that may influence the desire to hasten death. The literature has offered consensus regarding the impact of certain factors such as hopelessness and spirituality on “the desire to hasten death.” Research into factors such as depression and physical distress has shown inconsistent

results. The influence of social support has been shown to negatively correlate with “the desire for hastened death.” It will be important to learn more about the meaning of social support in the context of home hospice, as well as the interaction with perceived caregiver burden. This qualitative study will elicit patients’ individual perspectives on these factors and possibly elicit factors unique to the home hospice setting.

### **5.3 Study Aims**

**Aim 1:** This study employed qualitative methods to enable a deeper exploration of the factors that contribute to the “desire to hasten death.”

**Aim 2:** This study focused on the perspectives of home-based hospice patients in order to explore the influence factors within this specific environment.

**Aim 3:** This study generated qualitative data that will contribute to establishing a theoretical framework for the concept of “desire for hastened death.”

**Aim 4:** This study added to the existing empirical base, with preliminary development of practice guidelines that will better prepare hospice social workers to address a patient’s “desire for hastened death” in the home hospice setting.

## **Chapter 6: Research Design and Methodology**

### **6.1 Research Design**

#### **Research Questions**

- (1) In the unique environment of the private home, what factors contribute to a hospice patient’s “desire for hastened death?
- (2) If “the desire for hastened death” can be interpreted as an expression of distress, what are patients attempting to communicate about their needs?

(3) What additional new perspectives may be elicited through in-depth interviews about the “desire for hastened death”?

### **Setting**

This study partnered with Metropolitan Jewish Health System (MJHS) Hospice and Palliative Care. This large, New York City-based agency has a daily hospice census of over 900 hospice patients. Interviews focused exclusively on the home hospice population and took place in participants’ homes.

### **Participants and Recruitment**

Participants were recruited through collaboration with the social work department at MJHS Hospice and Palliative Care. Social workers at this agency are mandated to evaluate a patient’s suicide risk during the initial social work assessment that is completed with every new patient. After receiving approval from the University of Pennsylvania IRB, and the MJHS Research Committee, this study was introduced to staff at a mandatory monthly social work meeting in May 2015. During this meeting, the principal investigator presented this study to social work staff, and encouraged the social work team to refer appropriate candidates. Supplemental handouts were provided to staff advertising the study, and detailing inclusion and exclusion criteria. Additional copies of these handouts were also sent to all social work staff via email. The investigator addressed staff questions and concerns during the meeting, and remained available throughout the seven-month recruitment period to answer staff questions as they arose. Follow up announcements were made monthly during staff meetings, and via email to ensure that social workers maintained awareness of the study and continued to consider appropriate referrals.



Referrals were made directly to the investigator via secure confidential email. Staff members who were unclear about patient eligibility were encouraged to consult the researcher for clarification. All staff were provided with the primary investigator's phone and email contact information for any additional inquiries.

The principal investigator wrote a letter of introduction for potential participants to inform them of the study, provide an overview, and extend an invitation to participate if interested. In the original study design, paper and electronic copies of this letter were to be provided to agency social workers for distribution to potential participants during routine social work visits. However, upon consultation with the UPenn IRB, this protocol was identified as putting patients at risk for undue influence due to the relationships between hospice social workers and their clients. The study design was amended, and materials were instead delivered to patients via mail. These amended materials included an opt-in letter, and stamped, addressed envelope, in addition to the primary investigator's phone and email contact information, offering three ways for potential volunteers to reach out if interested. The researcher then followed up with interested individuals by phone, to offer clarification, and address any questions or concerns, as well as offer a respondent an opportunity to reevaluate participation, and either confirm interest and schedule an interview appointment, or opt out of participating.

### **Inclusion Criteria**

- Patients must be enrolled in MJHS Hospice Home Care services.
- Patients must be over 18.
- Patients must be English-speaking.
- Patients must have made some expression of a "desire to hasten death."

- Patients must be cognitively able to consent to, and, participate in, an in-depth interview. Patient participation is voluntary and he or she must have demonstrated willingness to discuss end of life issues.
- Patients must be verbal and physically able to engage in extended conversation.
- Patients must have been enrolled in hospice for a minimum of two weeks.

### **Exclusion Criteria**

- Patients who have cognitive impairments and lack capacity to sign consent forms.
- Patients who may be emotionally vulnerable and therefore unable to tolerate the discussion of sensitive topics.
- Patients with communication difficulties such as moderate to severe hearing impairments or speech impediments.
- Patients who have a history of suicide attempts, or are actively suicidal.

### **Sample Size**

This initial target for this study was 30 participants, who would consent, and volunteer, for in-depth interviews. Though sample sizes vary significantly among qualitative studies, others researching the “desire for hastened death” have suggested that 30 interviews should offer a wealth of information, while limiting theoretical saturation of the data (Back et al., 2002). After encountering difficulties with recruitment, the qualitative sample size was necessarily revised down. Over the seven-month recruitment period, from May 2015, to December 2015, 55 referrals were made. Of these 55 patients, 27 were deemed ineligible. Reasons for ineligibility included cognitive impairments (7), significant communication barriers (10), transfer off program (3), lethargy (3), death (2), active suicidal intent (1), and not open to end of life discussion (1). Study materials were

sent to the remaining 28 patients, of whom 27 did not respond to the invitation, and just one individual volunteered for an interview.

## **6.2 Qualitative Interview**

This qualitative study design employed a cross-sectional, semi-structured interview approach with home hospice patients. The researcher was prepared for challenges conducting in-depth interviews in a patient's home environment. The interviewer's priority was to maximize the comfort and ease for the respondent. The participant's physical and emotional needs were clearly stated as taking precedence over the integrity of the interview. Prior to beginning the interview, the investigator acknowledged this and expressed understanding in the event that a patient may need to take breaks in order to rest, address symptom needs, or terminate the interview early due to fatigue or discomfort. The investigator encouraged the respondent to interrupt or terminate the interview if such needs arose. The participant had no unusual needs during the interview, and no other unforeseen challenges arose.

The qualitative interview employed a written guide to maintain focus on research aims. These questions were intended as a guideline, with flexibility to explore other relevant issues that may arise. Interview questions were enhanced through the use of probe questions to expand and clarify patient responses. The interview focus was on developing a dynamic understanding of the individual respondent's perception of the "desire for hastened death" concept, as well as factors that contribute to these thoughts and feelings.

## **Interview Guide**

(This interview guide was completed with the assistance of Dr. Tracy Schroepfer, who is a consultant on this project, and portions of were adapted, with permission, from Dr. Schroepfer's previous work).

Thank you very much for allowing me to meet with you today. I appreciate your willingness to speak with me and answer questions. With your permission, I would like to record our discussion so that I can make sure I don't miss anything. I want to reassure you that everything you say is confidential.

### *Completion of Consent Form*

#### Demographics

Age:

Gender:

Marital Status:

Race/Ethnicity:

Religion/Spiritual Affiliation:

Educational Level (How many years of school have you completed?):

Employment (What kind of work did you do?):

Primary Diagnosis:

Time on home hospice:

I would like to talk to you about your feelings and experience related to your illness.

Some questions are personal and may be difficult to discuss. Please let me know if you feel uncomfortable at any time.

1) Would you tell me the main ways that your illness has affected your everyday life?

2) Has anyone discussed the likely outcome of your illness with you?

*If yes:* What do you know about your condition?

*If no:* What is your sense about what's going to happen?

*If patient does not appear to have appropriate understanding of his/her illness, skip to question 4.*

3) Sometimes, when people are facing a life-limiting illness, it can be natural for them to have thoughts of hastening their death. Have you ever had thoughts like this?

a) *If yes:*

i) Would you tell me more about these thoughts? About how often do you find yourself thinking about this?

- What is happening in your mind when these thoughts arise?

ii) Have you ever thought about how you might hasten your death? If so, what have you thought about? Are you pursuing this currently?

iii) Would you tell me about any specific reasons or factors that have led you to consider this?

iv) Have you spoken to anyone else about this?

4) I want to ask about your experience receiving hospice care at home.

a) Are there any parts your home hospice experience that have been especially stressful for you? Would you tell me about them?

b) Are there any parts of your home hospice experience that have been positive for you? Would you tell me about them?

5) Before we conclude our discussion, are there any issues or concerns about your illness experience that we did not cover and you would like to bring up now?

Please feel free to raise any concerns, offer feedback, or ask questions.

### **6.3 Data Analysis**

The interview was recorded and transcribed. The recording will be retained for three years, and the destroyed to protect patient privacy per IRB guidelines. This study used constructivist grounded theory methodology to analyze data (Charmaz & Belgrave, 2012). This is a method commonly used for qualitative research in health care settings, and has also been identified as an effective approach for interviewing individuals struggling with illness and isolation (Charmaz, 1990; Charmaz & Belgrave, 2012; Pope & Mays, 1995). Grounded theory is recognized as a comprehensive approach for capturing data within social and environmental contexts (Cutcliffe, 2000; Pope & Mays, 1995; Starks & Trinidad, 2007). This methodology is further suited for this analysis because it does not require a clear conceptual framework prior to analysis. Rather, grounded theory is an inductive method that seeks to develop or clarify concepts through the analytic process (Cutcliffe, 2000; Pope & Mays, 1995; Walker & Myrick, 2006).

Grounded theory is a systematic, three-step process that begins with identifying open codes through a line-by-line process of analyzing the data. Step two involves evaluating the open codes without the context of the original transcript in order to identify connections and refine open codes into broader categories, called axial codes. The final step examines, compares and connects the axial codes to identify central themes and concepts, known as ‘provisional’ codes (Cutcliffe, 2000; Starks & Trinidad, 2007;

Walker & Myrick, 2006). A constructivist interpretation of grounded theory recognizes the important influence that researcher, respondent, and the relationship between the two have on the research process (Charmaz, 1990; Charmaz & Belgrave, 2012; Mills, Bonner, & Francis, 2006).

## **Chapter 7: Case Study “Suffering year after year because Jesus is not ready for me”**

### **7.1 Setting**

This interview took place in the living room of the interview subject’s private apartment in New York City, at a time of her choosing. No other persons or pets were present at the time of this interview. This volunteer, “Diana,” was on a high concentration of oxygen, but she was able to make herself understood and continue the interview with few breaks to manage her breathing.

### **7.2 Patient Background**

Diana was a 65 year old, Christian, Hispanic woman diagnosed with a rare terminal illness that attacks the lungs, along with other body systems. Since Diana’s disease is not seen frequently, the name of her illness is withheld to protect her privacy. Diana was a high school graduate who resided with her daughter. At the time of the interview she had been followed by a home hospice agency for about six months. Due to the progression of her disease, Diana’s lung functioning was worsening. Diana reported that she was homebound due to not being able to travel with adequate oxygen coverage.

During the interview, Diana presented as open and direct. She showed little ambivalence or self-consciousness during her interview. She revealed that she had been

involved in a longitudinal research study about her disease for nearly twenty years, and appeared comfortable participating in another kind of research study.

### **7.3 Patient Interview**

This face-to-face interview was conducted by the primary investigator. The semi-structured inquiry followed the questionnaire written for this study. After completing the interview, content was transcribed for analysis using the three-step grounded theory model, beginning with open coding, progressing to axial coding, and concluding with the provisional codes discussed in this chapter.

To ensure that Diana maintained her capacity to consent herself for this study, she was given a Mini Mental State Exam (MMSE) (Folstein, Folstein, & McHugh, 1975). This volunteer non-verbally expressed annoyance with this step. After the patient had reached twenty-two points, though there were additional questions, this respondent had shown her capacity to consent, and the interviewer agreed to proceed without completing the remaining questions on the MMSE.

The respondent answered questions directly and was pleasant throughout the interview. She did not appear uncomfortable discussing deeply personal issues. One issue noted in the content of this interview guide arose in Section 3: a: iii, which reads “Have you ever considering seeking a means to hasten your death?” There seemed to be misinterpretation with the language on this question. The respondent did not appear distressed by the question, but interpreted the term as referring specifically to suicide. She reported passing suicidal ideation, but discussed feeling traumatized by recent suicides in her building and stated, *“I would never do that to my daughter.”*



The issue with unclear wording was reinforced later in the interview when this volunteer broached the topic of the “desire for hastened death” herself. She brought up the topic through referencing the case of Brittany Maynard, a terminally ill young woman, who had very publicly moved from California to Oregon so that she could access physician-assisted death (PAD) when her quality of life became intolerable. Diana had many thoughts and feelings on this issue, and she undoubtedly would have responded more comprehensively had the question been phrased in a manner more accessible to this participant. Question 3 has been expanded for future usage of this interview guide, and will now begin with the following preface: *Researchers studying hospice discuss the idea of patient “desire for hastened death.” Have you ever heard this term? What does this term mean to you?* The goal of this revision is to engage the respondent in a discussion and clarification of his or her understanding or interpretation of the “desire for hastened death.”

#### **7.4 Results: Provisional Categories**

##### ***Ongoing Physical Suffering***

The aforementioned process of data analysis yielded nine provisional categories. The first was *ongoing physical suffering*. This respondent spoke about feeling that she is currently suffering with her worsening shortness of breath. She also described getting winded after a few steps and having areas of pain, such as her nose, which bleeds frequently. Diana spoke about feeling more and more fatigued all the time, trying not to sleep during the daytime, while needing medications to enable her to sleep at night. When speaking about hastening death, she asked, *“I have to suffer year after year after year because Jesus is not ready for me?”*

### ***“There’s Always Something on My Mind”***

In addition to her physical suffering, another theme through her discussion was recent mental health challenges. The sleeping discussed above is also an example of the emotional difficulties Diana faced. She spoke about depending on morphine and lorazepam for sleep, and her discomfort with needing these medications. She stated, *“It’s not normal sleep.”* She described her day as *“Falling Asleep. Waking Up. Falling Asleep.”* The respondent stated that these dysregulated sleep patterns made her feel down. She also described a recent history of anxiety, hallucinations and worries about the future course of her illness. This was distinct from the current literature about factors related to hastened death, as Diana did not have a history of psychiatric illness, but was instead impacted by mental health concerns such as the hallucinations that developed as her disease progressed.

### ***Waiting Alone for Several Hours***

During the interview, Diana spoke at length about the amount of time she spent at home alone. She discussed the home health aide services that she received through her hospice program, which were limited to only four hours per day. She lived with her daughter, whom she described as *“otherwise engaged,”* busy managing work and school, in addition to her role as caregiver for her mother. She spoke positively about the frequent visits made by hospice staff, but also described loss of the social life she had enjoyed before the disease had progressed. Diana described what her expectations had been when she was in the hospital and decided to go home with hospice care. She had expected to be able to go out with her daughter, shopping and having dinner. Instead, due to her high oxygen requirement, since returning home, she’d had to remain in her

apartment. Diana returned several times to the discussion of her homebound status, limited aide hours, and daughter's busy schedule.

### ***Struggling with the Impact of Illness on the Mother/Daughter Relationship***

Her young adult daughter was the most prominent topic during Diana's interview. She spoke about her daughter in several different contexts. Some addressed positive aspects of their current situation, such as her pleasure in seeing her daughter every day. She also voiced concerns about how she and her daughter would miss each other if she needed to transition to an inpatient hospice facility. She touched upon more challenging aspects of the current situation when she spoke about her daughter's inexperience with illness and caregiving. Diana stated, "*She (the daughter) only knows taking care of her.*" She spoke about her daughter's busy schedule and unwillingness to talk about dying. She also suspected that others may have been critical of her daughter's efforts, and spoke about her daughter feeling the need to defend the job she had been doing as Diana's primary caregiver. Finally, Diana also discussed her concern about her daughter's coping. She expressed worry about her daughter having to see her get sicker and possibly go to an inpatient hospice facility. Diana described wanting her daughter to speak to hospice staff and attend support groups, but her daughter had not been interested. These complex issues make up the provisional category *struggling with the impact of illness on the mother/daughter relationship*.

### ***Would Take PAD Option if Available***

When Diana discussed the topic of hastened death through the case of Brittany Maynard, the terminally ill woman who'd moved from California to Oregon to access physician assisted death (PAD). Diana spoke about her support for Brittany Maynard and

stated, *“That sounds so nice the way she did it with her family.”* She also revealed an up-to-date knowledge of states where PAD was legal. It was clear that Diana had been following these issues. She observed, *“I can’t move to Vermont or any of those states.”* She stated that if New York had access to PAD, she would pursue it. She recognized that this was unlikely to happen soon, and stated, *“So I go back to feeling bad.”* During her discussion of PAD, Diana spoke about her own beliefs. She described the sentiments of those around her who told her that PAD was like suicide, telling her, *“You have to wait till Jesus is available for you.”* Diana stated, *“I don’t consider this suicide.”* She inquired, *“How can it be suicide if Jesus provides the means to do it?”*

#### ***Wanting to Talk About PAD, but Others Uncomfortable with Conversation***

The exchange described above is one of many instances where Diana described a scenario where she wanted to talk about her illness and eventual death, as well as her feelings about PAD, but did not find an audience. When she spoke about PAD, she spoke about people not liking that discussion. When she described broaching the conversation with others she observed, *“Most of them don’t touch—they don’t like it.”* With regard to her daughter, Diana remarked, *“We never talk like that.”* She said, *“That’s what I would like to do, sit and talk about the topic.”* However, when she’d attempted such conversations, Diana reported, *“She says I talk about weird things.”*

#### ***Fear of Worsening Physical Symptoms as Disease Progresses***

When Diana spoke about her interest in PAD, she spoke first in reference to the case of Brittany Maynard. In discussing Brittany Maynard’s decision to pursue PAD she observed, *“She’s not going through any pain.”* She then focused on her own fears of the impact of her disease progression. Many of these fears related to her worsening ability to

breathe. She described her fear of running out of oxygen and her worry about timely access to higher flow oxygen when her current oxygen machine was inadequate. She worried about feeling, after hearing her physician's description, *"like a fish out of water."* In addition to breathing concerns, she spoke about pain in the future. Though breathing was her primary physical concern at the time of the interview, she also described *"feeling like I'm gonna be in pain."* Diana connected her wish to pursue PAD to her worry about pain during disease progression.

### ***Importance of Choice***

One aspect of PAD that Diana touched upon several times was the opportunity to make a choice. She disagreed with those around her who equated PAD to suicide, while she considered it a choice in the course of terminal illness. She called this *"suicide versus one more choice."* Diana highlighted the lack of choice when describing what she envisioned for the end of her life. She asked, *"What are my choices?"* When she described the course of her illness, she spoke about one of the few treatment choices she had faced, which was whether or not to pursue lung transplant. She noted that even with transplant, she might have only extended her life by five years. She then spoke about that choice having been taken away when she was informed that she did not qualify for the transplant. At that point, she said her physicians told her she should enter hospice, and, *"From then on, I've been here."* When she spoke about hastening her death through PAD, the fact that it was a choice appeared very significant to her, and while others saw PAD as a kind of suicide, she perceived it as a final choice that one with terminal illness may have the opportunity to consider.

### ***Making Contributions to Science and Research***

At the beginning of this interview, Diana detailed her past experience with research studies, and she continued to refer to research throughout the interview. She had participated in a study of her illness for nearly twenty years and verbalized her familiarity with many aspects of research, from participation, to publication, to professional symposiums. Diana indicated her understanding of the importance of research when she spoke about wanting to help researchers through her participation in this study, as well as the other longitudinal study in which she had participated. However, she showed conflicting feelings about research when she pointed out that there had been limited research on her illness because it does not affect children. She also noted that she was not going to give future tissue samples for her longitudinal study because she did not want to “go through that” any longer. Her cognizance that this interview was a part of a research study emerged as a theme throughout her discussion. Diana showed her understanding of the research process, as well as curiosity about where her contribution would lead, when she asked, “*Who will publish this story?*”

### **7.5 Outcomes**

This participant’s discussion of the “desire for hastened death” primarily focused on physician assisted death (PAD). She was well informed about legal factors and current events related to PAD. She appeared to welcome the opportunity to discuss a topic that she felt friends and family wished to avoid. Diana had clearly thought about this option for herself. Her use of the word “choice” was unique, but also consistent with current research indicating the importance of considering hastened death in providing a sense of control and autonomy for some terminally ill patients.

When she spoke about what motivated her to pursue PAD, she cited her fear of future pain from her illness. Though pain was not her primary complaint at the time of the interview, she was concerned about having more pain as her disease progressed. This reinforces research findings, which consistently identify the correlation between fear of future physical suffering and the “desire to hasten death.” She also spoke of her fear of being alone at home, unable to breathe, and unable to access a higher level of oxygen. While patients in various settings describe similar fears, Diana’s worries were specifically focused on being home alone and having timely access to care, two concerns that may be elevated in the home hospice setting.

Though these were the factors that this participant cited as directly contributing to her interest in PAD, it is important to note that there were several factors discussed during the interview that she indicated as stressors which affected her quality of life. Of these, her worsening breathing and the challenges in her relationship with her daughter, now, caregiver, were the issues Diana mentioned most frequently. Diana’s struggles with the changes in her relationship with her daughter illustrate the complex influence of social support that may be unique to the home care setting. The respondent also described her challenges with her homebound status, social limitations, disordered sleep, and periods of anxiety, depression and hallucinations. Additionally, Diana made several references to conversations about dying that she was unable to have due to loved ones’ discomfort with the subject. She spoke briefly about pain, but spoke more about an overall sense of ‘suffering,’ a term she may have used to characterize her general state of being a terminally ill person. Diana’s discussion of suffering recalls Balaguer’s

“international consensus definition” which considers the “desire to hasten death” a reaction to suffering in terminal illness (Balaguer et al., 2016).

## **Chapter 8: Discussion**

### **8.1 Agency Challenges in the Research Enterprise**

This qualitative research study was reduced to a single case study due to several challenges. The overarching challenge was collaborating with an agency that had only recently expanded to include a research institute. Although some researchers affiliated with the institute had ongoing projects, no research had yet been initiated through the agency. The research institute is a separate entity from the hospice agency, and there is not day-to-day collaboration between them. Institute staff are primarily focused on expanding research opportunities within the broader agency. By contrast, hospice staff are busy clinicians devoted to patient care, who have demonstrated little availability for promoting research.

Though this study enjoyed the support of the researchers on the institute side, the hospice clinicians rightly prioritized the needs of their patients. In addition to demands of social work as a field, stereotyped as “overworked and underpaid,” the home hospice role requires travel from home to home, which takes additional time, and in New York, with traffic and reliance on public transportation, can certainly increase stress levels. At baseline, these social workers are working extremely hard, and with the high likelihood of urgent issues and crises arising at end of life, it is understandable that the task of making referrals for research study could easily be lost among more pressing responsibilities.



The primary investigator attempted to address this with ongoing reminders during meetings, and emails between meetings. Well known to the staff, the researcher explored ways to make the referral process easier for social workers. The social workers agreed that they needed email reminders, but with brimming inboxes, did not want too many reminders. The social workers determined that it would be most helpful to receive one email between monthly meetings, and the investigator complied. Another barrier to referrals that the researcher identified based on social worker questions was lack of clarity regarding inclusion criteria. It is notable that, despite education, some social workers did not understand the concept of hastened death and its dimensions beyond active thought and pursuit of ending one's life. This was addressed through a brief presentation at the July 2015 staff meeting, which clarified concepts and eligibility criteria. Social workers were encouraged to inquire about or submit any questionable referrals, which the primary investigator would evaluate for eligibility.

Despite these attempts to increase referrals, numbers remained low. In fact, with a staff of nearly fifty social workers, only eleven actually made a referral for this study. There were several reasons that may have contributed to these low response rates. The primary reason may be the demands of the hospice social work role. Though it was never stated, it is possible that some social workers may have been protective of their patients, and felt more comfortable avoiding the study altogether. Still others may have simply been apathetic about the study, and uninterested in taking the time to make referrals. It is very unlikely to be related to appropriate patients for referral. The literature suggests that up to 55% of terminally ill patients make some expression of desiring hastened death

(Wilson et al., 2014). Considering these statistics and the large census at this hospice, this may be an indication that a number of eligible patients were not referred.

## **8.2 Study Issues**

With the limited number of referrals contributing to low recruitment, issues with the study design were also limiting factors. Outreach was a primary challenge due to the risk for undue influence if social workers were to deliver materials to patients. Mail delivery was a poor alternative. In many cases, loved ones and caregivers collect and sort mail for patients, and some may have discarded study materials without ever passing along the information. People may also be prone to discard mail from unknown senders as junk. Study materials were hand addressed and sent in colored envelopes in an attempt to overcome some of these barriers, but even with these enhancements, mail remains a passive form of outreach.

How could recruitment be improved? Few patients check email regularly, and phone outreach could prove confusing, with too much information to be communicated. There are few good options here. One of the most profound weaknesses in this study design was the absence of a phone call protocol, including a schedule of follow-up phone calls after initial materials were sent. It is unclear how much this would have improved recruitment, but follow-up phone calls would alert patients to materials that may have been missed in the mail. This would also provide an opportunity to resend study information to potential volunteers who may have been interested, but missed the initial mailing.

There are numerous areas for improvement in future studies. However, the low recruitment in this study also underscores the challenges of research with home hospice

patients. In addition to difficulties with outreach, this population is likely to encounter variable physical and cognitive functioning, and even if referrals were plentiful, this would remain a difficult population to study.

## **Chapter 9: Practice Guidelines in Addressing the Desire for Hastened Death**

The purpose of this study was to gain more nuanced understanding of the “desire for hastened death” through qualitative research with home hospice patients. The ultimate goal in researching hastened death is to understand patient needs and motivations, so that clinicians working in hospice care may be better educated and equipped to support these clients. Given the single participant in this study, there is not enough data to inform directions for future practice. In the absence of guidelines generated from this study, this section will explore current literature about assessment and intervention with patients expressing “the desire for hastened death” in order to offer clinical direction for the social workers addressing these needs.

### **9.1 Consensus Guidelines**

Given the disparate nature of research on the concept of “desire for hastened death,” it is not surprising that current practice guidelines are both wide-ranging and, often, inadequate. Guideline reports published by professional associations rarely address the concept of “desire for hastened death.” Rather, one must look to position papers responding to physician-assisted death (PAD) (American Academy of Hospice and Palliative Medicine, 2007; American Nurses Association, 2013; Gallagher-Thompson & Canetto, 1999; Hospice and Palliative Nurses Association, 2011) or reports on Standards for Hospice and Palliative Care for practitioners (Gwyther et al., 2005; Institute of

Medicine, 2014; National Association of Social Workers, 2004). Many of these reports offer some insight for an assessment of a patient's "desire for hastened death" (American Academy of Hospice and Palliative Medicine, 2007; Hospice and Palliative Nurses Association, 2011). This section will also discuss relevant international research.

### **Specialist Referrals**

Several guidelines simply direct clinicians to consult an expert or refer to a mental health specialist when faced with desire to die statements (Abrahm, 2008; American Academy of Hospice and Palliative Medicine, 2007; American Nurses Association, 2013; Tulsky, Ciampa, & Rosen, 2000). These 'experts' are often defined as hospice and palliative care practitioners, without identifying a discipline within that group (Abrahm, 2008; Black, 2005; Black & Csikai, 2015; Gwyther et al., 2005; Hudson et al., 2006; Reese, 2011; Weisenfluh & Csikai, 2013). Few guidelines identified in this research distinguish between the roles of hospice and palliative care clinicians, and no literature was found offering guidelines explicitly for home hospice social work. Since the majority of the research in this area has been with inpatient populations, it may be deduced that these guidelines are primarily designed for inpatient care. One notable distinction, when contrasting facility-based care from home hospice care, is the availability of psychologist and psychiatrist consultants. While social workers remain the primary providers of psychosocial services in health care facilities, there may be other mental health clinicians with different backgrounds available to consult and collaborate on challenging cases. The home hospice setting is unlikely to offer the same breadth of mental health services, so it becomes that much more imperative for these social workers to have the knowledge and skills to intervene with patients who express a desire to hasten death.

## **A Call for Education**

One of the most important means for acquiring these clinical skills is through education. Numerous papers cite the need to expand education in responding to patient expressions of “desire for hastened death” (American Nurses Association, 2013; Arnold, 2004; Cagle, Pek, Clifford, Guralnik, & Zimmerman, 2015; Gwyther et al., 2005; Hospice and Palliative Nurses Association, 2011; Institute of Medicine, 2014; Meghani & Hinds, 2015; National Association of Social Workers, 2004; Walsh, Corbett, & Whitaker, 2005; Weisenfluh & Csikai, 2013). However, among these many mentions, the specific nature of the educational needs is rarely detailed beyond professional development. For the purpose of this discourse, proposed educational strategies will be described including guidelines, skills, and interventions that may advance the hospice social worker’s proficiency in addressing a patient’s “desire for hastened death.”

## **Evaluating Capacity**

The literature does offer consensus in specific areas of competency. One such standard is the necessity of assessing patient cognition prior to determining a clinical course (Abrahm, 2008; American Academy of Hospice and Palliative Medicine, 2007; Black & Csikai, 2015; Gwyther et al., 2005; Macleod, Wilson, & Malpas, 2012; National Association of Social Workers, 2004; Tulskey, Ciampa, & Rosen, 2000). While lack of decisional capacity should not preclude clinical intervention, it may inform the style of intervention, and also has the potential to limit access to certain concrete legal interventions.

## **Value of Advance Care Planning**

Advance care planning is an example of an intervention that would necessarily be limited by patient cognition. The impact of advance care planning is frequently explored in the research on hastened death (Black & Csikai, 2015; Detering, Hancock, Reade, & Silvester, 2010; Gallagher-Thompson & Canetto, 1999; Gwyther et al., 2005; Institute of Medicine, 2014; Meghani & Hinds, 2015; National Association of Social Workers, 2004; Reese, 2011). Advance care planning often results in the generation of legal documentation, such as a living will, empowering a patient to express and direct his or her treatment preferences. Conferences may encourage open discourse about end of life issues among patients, clinicians and loved ones, and may also promote patient autonomy through self-directing care (Black & Csikai, 2015). Research on this topic suggests positive outcomes, including increased patient and family satisfaction and decreased stress, anxiety and depression among surviving family members (Detering, Hancock, Reade, & Silvester, 2010).

Two reviews offer some cautionary points about the benefits of advance care planning due to extent and complexity of paperwork and reports of poor adherence to directives when patients are incapacitated (Black & Csikai, 2015; Castillo et al., 2011). Despite these serious concerns, studies have shown that the advance care conversation, itself, has a therapeutic function for patients and loved ones (Castillo et al., 2011; Detering, Hancock, Reade, & Silvester, 2010). Furthermore, a qualitative study with terminally ill elders revealed exclusion from care discussions and decision-making as central to the acuity of patient suffering, and the primary reason that patients desired hastened death (Schroepfer, 2007).

## **Open Communication**

Schroepfer's (2007) findings underscore the profound importance of open, effective clinician communication. This approach directs providers to approach desire to die discussions with respect and empathy. These discussions can often be difficult for both clinicians and patients, but the clinician's ability to remain engaged and hear patient concerns can, itself, be therapeutic (Tulsky, Ciampa, & Rosen, 2000). This fundamental guideline is emphasized throughout the research on hastened death (American Nurses Association, 2013; Back et al., 2002; Balaguer et al., 2016; Black & Csikai, 2015; Branigan, 2015; Csikai, 1999; Institute of Medicine, 2014; Macleod, Wilson, & Malpas, 2012; National Association of Social Workers, 2004; Starks et al., 2005; Tulsky, Ciampa, & Rosen, 2000). Research on the "desire to hasten death" consistently advocates use of open, non-judgmental communication with patients. This becomes more difficult in a scenario where patient and provider disagree about sensitive ethical issues. A clinician's ability to overcome personal differences, remain open, and maintain therapeutic engagement has been reported to enhance the clinical relationship (Back et al., 2002). This level of open, empathic communication, and exploration of sensitive subjects is a clinical skill that can engender patient trust and provide comfort for vulnerable individuals struggling to cope with terminal illness (Balaguer et al., 2016; Quill, Back, & Block, 2016).

## **Exploring Clinician Values**

Developing the skill to engage in this level of open communication requires effort on the part of the clinician. To effectively facilitate discussion about often-divisive issues, practitioners must prepare for this work by examining their own beliefs, values,

fears and biases about dying, and end of life decision-making. This self-reflection is widely cited as fundamental in a provider's ability to effectively address these complex patient needs (Black, 2005; Black & Csikai, 2015; Block & Billings, 1994; Branigan, 2015; Csikai, 1999; Gallagher-Thompson & Canetto, 1999; Gwyther et al., 2005; Hospice and Palliative Nurses Association, 2011; National Association of Social Workers, 2004; Quill, Back, & Block, 2016; Tulsky, Ciampa, & Rosen, 2000; Werth & Holdwick, 2000). The literature acknowledges that practitioners represent a varying range of deeply held personal beliefs with respect to end of life and the "desire for hastened death" (National Association of Social Workers, 2004; Norton & Miller, 2012). Clinician values about end of life choices are shaped through all aspects of the individual clinician's history, including family history, professional experience, and spiritual beliefs (Black, 2005; Csikai, 1999b). Whether conscious or unconscious, a clinician's core beliefs will influence practice. Professionals who have not confronted personal challenges with related to end of life, risk ongoing discomfort that may undermine the quality of therapeutic relationships with patients (Black, 2005; Block & Billings, 1994). If a practitioner determines that he or she cannot offer adequate patient care in the context of insurmountable value differences, he or she is responsible for the transfer of care to best support patient needs (Hospice and Palliative Nurses Association, 2011).

### **Client-Centered Care**

The literature is prolific in proposing practice frameworks for assessing the "desire to die" statements. Throughout the broad-ranging recommendations, there is one, near universal, first step. Guidelines encourage clinicians to adopt a patient-focused, individualized approach to care (Altilio, Gardia, & Otis-Green, 2008; Block & Billings,



1994; Block, 2001; Branigan, 2015; Breitbart, Gibson, Poppito, & Berg, 2004; Byock, 2002; Chochinov et al., 2011; Gallagher-Thompson & Canetto, 1999; Gwyther et al., 2005; Institute of Medicine, 2014; Krikorian, Limonero, & Maté, 2012; Meghani & Hinds, 2015; National Association of Social Workers, 2004; Norton & Miller, 2012; Quill, Back, & Block, 2016; Schroepfer, Linder, & Miller, 2011; Van Loon, 1999). The client-centered, person-in-environment perspective is a core social work ethic, and common in most therapeutic interventions (Altilio, Gardia, & Otis-Green, 2008; Gwyther et al., 2005). This perspective provides a natural foundation for the development of practice guidelines to address and support those struggling with the desire to hasten death.

## **9.2 Assessing the Desire for Hastened Death**

Literature on hastened death is replete with frameworks for assessing patient desire to die statements. These guidelines offer various approaches to evaluate “desire for hastened death.” Some offer a structured approach, such as the American Academy of Hospice and Palliative Medicine (AAHPM). This five-step guide directs practitioners to (1) Determine the nature of the request, (2) Clarify causes of suffering, (3) Evaluate decision-making capacity, (4) Explore emotional factors (5) Explore emotional factors (American Academy of Hospice and Palliative Medicine, 2007). The American Psychological Association (APA) provides a six-question guideline, (1) Is medical care accessible and adequate? (2) Are palliative care and pain management adequate? (3) Are the psychosocial needs of patients and loved ones being addressed? (4) Are cultural issues being addressed? (5) Are spiritual and existential needs being addressed? (6) Is the physical disease process or treatment for the disease creating emotional distress or

cognitive impairment (Gallagher-Thompson & Canetto, 1999)? Back and colleagues offer an alternate six-step guide to assessing desire to die statements, beginning with (1) be open and explicit, (2) Ask the patient what he or she hopes for in the dying process, (3) Offer to discuss how to facilitate a patient's desired dying process, (4) Check the patient's understanding of the discussion, (5) Recognize that building a therapeutic relationship is more important than providing a prescription, and, (6) Clinicians must self-monitor involvement in patient relationships (Back et al., 2002).

Rather than offering a systematic approach, some guidelines provide lists of areas to explore in evaluating the "desire for hastened death." Block and Billings (1994) describe four domains for assessment, including physical symptoms and their management, difficulties in interpersonal relationships, psychological needs and their management, and a patient's personal values related to suffering, control and the dying process (1994). An alternate list of areas to assess includes adequate clinician involvement, pain and symptom management, psychological disorders, fear of future suffering, strained family relationships, dysfunctional family dynamics, and personal values related to suffering and self-reliance (Abrahm, 2008).

Several assessment tools focus on more specific areas of assessment. One such approach directs clinicians to explore dimensions of patient suffering, including physical, psychological and existential suffering (Starks et al., 2005; Tulsky, Ciampa, & Rosen, 2000). In Krikorian's (2012) review of the literature, the author offers a fourth dimension, sociocultural suffering. Some of the research studies conclude with specific areas to explore based on outcomes. Ganzini and colleagues (2008a) direct clinicians to focus on factors related to future fears related to disease progression. This includes anxiety about

dying, as well as future loss of dignity, control, independence, and ability for self care. A nursing guideline echoes several of the above guidelines, and recommends assessing concerns about loss of autonomy, dignity, and ability to engage in activities that make life enjoyable (Hospice and Palliative Nurses Association, 2011). Other studies guide practitioners to evaluate directional correlates such as increases in depression, pain, and anxiety, and decreases in hope and social support (Arnold, Artin, Person, & Griffith, 2004). The literature offers some consensus in areas of assessment, as evidenced in the similarities among these guidelines.

### **Assessment: Social Work Perspective**

Since this review is focused on social work practice, literature from this field is particularly relevant. The social work profession uses a holistic model of assessment in all areas of practice. This ‘biopsychosocial-spiritual’ approach instructs clinicians to consider biological, psychological, social, and spiritual domains when assessing clients (Csikai, Roth, & Moore, 2004; Gwyther et al., 2005; National Association of Social Workers, 2004). This model could offer a comprehensive approach to evaluating the multifactorial motivations influences on the “desire for hastened death” (Csikai, Roth, & Moore, 2004).

Social work literature offers two comprehensive models for exploring “desire to die” statements (Miller, Hedlund, & Murphy, 1998; Van Loon, 1999). Recognizing that traditional mental health assessments of suicidal intent would not be effective for hospice patients, Miller (1998) developed guidelines to address unique needs of this population. This three-part assessment begins by exploring “Presenting Concerns,” including diagnosis, prognosis, symptoms, emotions, and care needs. This is followed by “Meaning

and Culture,” which examines factors like spirituality, ethnicity, economic status and sexual orientation. This second domain is designed for evaluating patients, as well as their loved ones. The last area of assessment is the “Psychosocial Environment” of both the individual and the family. For the individual this indicates age, gender, cognition, hopes, fears, loss of dignity, burden, and body image. For the family, this speaks to helplessness, communication, roles, and supports (Miller, Hedlund, & Murphy, 1998). This third domain is extremely broad, and it could prove overwhelming to explore so many factors at once. Simple refinements like separating assessments for the individual and the family might make this assessment more manageable for clinicians.

Van Loon (1999) presents a very different approach with her decision tree assessment model. Following a “desire to die” statement, this framework begins by exploring for depression, citing criteria specific to seriously ill patients. If depressed, the ‘yes branch’ leads to assessment of suicide, referencing risk factors for terminally ill patients. If a patient is suicidal, clinicians must first prioritize safety precautions, and then treat the patient for depression. If the patient is depressed, but not at risk for suicide, this model recommends clarification and education, social support measures, psychotherapy, and medication.

The other side of the decision tree model, the ‘no branch’ applies to patients who did not present as depressed. This branch also begins with an assessment of suicidal intent. If the patient is found to have suicidal intent the ‘yes branch’ indicates that this patient’s “desire to die” is based on rational choice. The clinical recommendation to address rational choice is to explore and facilitate decision-making without judgment, and, in states with legal physician-assisted death (PAD), make appropriate referrals.

Returning to the exploration of suicidal intent, the ‘no branch’ directs clinicians to assess whether someone is ‘questioning,’ meaning that person has no active suicidal intent, but continues to have passive thoughts of ending his or her life. This model suggests that, in this context, “desire to die” talk is a coping mechanism that can enhance one’s feeling of control, as well as function as a therapeutic expression of existential distress. This model recommends that, for these patients, intervention should focus on normalization, through encouraging patients to express themselves, and validating their thoughts and feelings. The final branch on this decision tree is for a patient no longer ‘questioning,’ or considering suicidal intent. In this framework, this branch indicates acceptance, and recommends a therapeutic goal of affirmation. Van Loon contends that acceptance may be grounded in spirituality, and for those patients, clinicians should consider collaborating with chaplaincy (Van Loon, 1999).

This decision tree is an older model with some limitations. “Desire for hastened Death” is a recognized concept that is distinct from suicide, and the current literature emphasizes this distinction. A model developed today would be unlikely to use the word suicide, and if suicide were addressed, it would only appear on a low branch. Additionally, the framework identifies depression as the primary determinant in desiring hastened death, which hinders exploration of the many other significant contributing factors.

This model also has significant strengths. The decision tree represents a methodical approach to assessment, outlining a thought process that could be useful in assessing a wide range of influences. Perhaps the most notable aspect of this model is that the results are presented with guidelines for intervention. Current practice guidelines are

primarily focused on understanding why a patient desires “hastened death,” with little direction for intervention once reasons are identified. Some guidelines recommend general psychotherapy to address identified needs. Supportive psychotherapy is a fundamental skill in hospice social work practice. Social workers need a more nuanced skill set to adequately address these complex challenges.

### **9.3 Interventions**

Moving beyond frameworks for assessing the “desire for hastened death,” the literature offers very limited instruction on clinical interventions for addressing identified patient needs (Branigan, 2015; Breitbart et al., 2012; Breitbart, Gibson, Poppito, & Berg, 2004; Hudson et al., 2006; Rehmann-Sutter, Gudat, & Ohnsorge, 2015). The growing interest in the “desire for hastened death” has yielded growing exploration of therapeutic interventions, but current research remains limited, and primarily comprised of expert recommendations, rather than evidence-based practices (Hudson et al., 2006). There are many reasons for this, including the relatively recent emergence of the concept of “desire for hastened death.” Other reasons include the lack of therapy specific to terminally ill patients in general (Breitbart & Rosenfeld, 1999). Another reason may be that the multifactorial nature of “desire to die” expressions may prove too broad for a single therapeutic approach (Branigan, 2015). This is even more notable in the realm of home care, as most current research focuses on inpatient interventions (Hudson et al., 2006).

The purpose of this review is to explore interventions that are accessible and useful to home hospice social workers. This recognizes the breadth of the hospice social work role and the limits these clinicians may have in accessing in-depth training in specific psychotherapies. It should also be noted that pharmacotherapies are available to

address patient needs like depression, pain, anxiety, and shortness of breath. It is implicit in the hospice social work role that clinicians collaborate with nurses and physicians on their interdisciplinary teams to address these needs with appropriate medications. This review assumes that such collaborations should be taking place concurrent to psychotherapies.

### **Cognitive Behavioral Therapy**

Cognitive Behavioral Therapy (CBT) is a commonly cited evidence-based intervention, used to address a broad range of psychosocial needs. There is some empirical evidence and practitioners have observed, that this psychotherapy is also effective for patients with terminal illness (Anderson, Watson, & Davidson, 2008; Branigan, 2015; Chochinov & Breitbart, 2009; Gwyther et al., 2005; Kumar, Morse, Zemenides, & Jenkins, 2012; Van Loon, 1999). This intervention targets the connectedness of an individual's thoughts, feelings, and behaviors, and uses this dynamic to identify and challenge unproductive, or negative, thoughts (Anderson, Watson, & Davidson, 2008; Chochinov & Breitbart, 2009; Kumar, Morse, Zemenides, & Jenkins, 2012). This may include "alternation of ongoing self-statements, images and feelings that interfere with adaptive functioning; alteration of cognitive schema that give rise to habitual ways of construing the self... and alteration of maladaptive behaviors" (Chochinov & Breitbart, 2009, p. 474). This approach can empower patients to feel more in control of their mental health (Kumar, Morse, Zemenides, & Jenkins, 2012).

In a small feasibility study, cognitive behavioral techniques were found to lessen patient anxiety and depression (Anderson, Watson, & Davidson, 2008). Results found that the most helpful techniques included 'linking thoughts, feelings, behaviors, and

physical symptoms,’ ‘diaries, weighing advantages and disadvantages,’ ‘identifying and challenging negative thoughts,’ ‘creating goals and planning activities,’ and ‘creating a list of questions for the doctor.’ This study was time limited and patients saw benefits in three to four sessions. The sample size in this study was eleven hospice patients, so this requires further study, but results were promising. The authors do caution that clinicians should be judicious in using this approach, which would not be appropriate for patients who have poor energy or cognitive deficits, such as poor concentration, or memory loss (Anderson, Watson, & Davidson, 2008).

These cognitive behavioral techniques are accessible to hospice social workers, and could be easily learned and integrated into current practice. Researchers also indicate that these techniques can be flexible and do not need to be used in dedicated sessions. Thus, hospice social workers may be trained in the cognitive model, and identify particular cognitive behavioral tools appropriate for specific patient needs.

### **Mindfulness**

Many of the recent iterations of behavioral therapy include mindfulness practices (Öst, 2008). These therapies, such as Acceptance and Commitment Therapy (ACT), and Dialectical Behavioral Therapy (DBT) may be too complex for both clinicians and patients to appropriately integrate into hospice practice. However, mindfulness is a concept that describes several practices, including those focused on centering and relaxation, such as breathing exercises, progressive muscle relaxation and imagery, which may be important approaches in hospice care. Studies of mindfulness with terminal patients remain limited. One small Dutch study looked at mindfulness interventions in patients with metastatic breast cancer and found improvements in patient mood, increased



acceptance of illness, decreased fear, fewer physical complaints, and decreased negative thoughts (Visser, de Witte, Speckens, Prins, & van Laarhoven, 2015). Another Japanese study looked at mindfulness in cancer patients and outcomes were notable for lower anxiety and depression (Ando et al., 2009). This study is particularly relevant as it involved one guided session, followed by patients practicing mindfulness techniques at home, using a CD or DVD.

Simple mindfulness practices could easily be integrated into hospice social work practice. Clinicians could learn one of any number of simple breathing exercises in minutes, though they must be judicious in the use of such techniques, which cannot be used with patients experiencing shortness of breath. Progressive muscle relaxation is a technique where one focuses on different muscles in the body and works to release tension, usually systematically throughout the body. This practice can help individuals release tension, while maintaining or improving a sense of bodily control (Chochinov & Breitbart, 2009). Again, clinicians should be cautious in identifying patients who are physically and cognitively able to participate in this practice. A third mindfulness practice that would be useful in working with hospice patients is imagery. This can either be guided or individual, and describes intense focus on an image that is in some way supportive for a patient. This may be an image that encourages strength or optimism, or most often, encourages relaxation, such as imagining oneself in a forest or at a beach (Chochinov & Breitbart, 2009). Imagery requires focus from a patient, but for patients who are less alert and able to actively participate, descriptions or sounds of comforting imagery may still offer a benefit.

Any of these mindfulness techniques could be easily taught to those hospice social workers that are not already familiar with the practices in one brief session. These techniques have shown to benefit a range of emotional, physical and existential suffering. Furthermore, for any social workers uncomfortable engaging in these practices themselves, there are numerous smart phone applications offering mindfulness practices. Social workers could use these applications with patients or educate patients and their loved ones, who have phones or computers, to access these tools.

### **Dignity Therapy**

There are currently only two therapeutic interventions designed specifically for this patient population, one being Dignity Therapy. It is widely accepted that dignity is a critical concern among patients facing end of life, and loss of dignity is often cited by patients expressing a “desire to hasten death.” Chochinov and colleagues (1995) became interested in dignity through studying the “desire for hastened death.” As their research into hastened death evolved, they focused on the construct of dignity for terminally ill patients (Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002; Chochinov et al., 2006). This led first to the development of the Patient Dignity Inventory (PDI), a twenty-five-item scale designed to measure and assess the nature of a patient’s “dignity-related distress” (Chochinov et al., 2008). Patients are asked to rank each statement on a scale of one ‘Not a problem,’ to five, ‘An overwhelming problem.’ Statements include “Worrying about my future,” “Feeling that I am a burden to others,” and “Not being able to accept the way things are” (Chochinov et al., 2008). This scale is offered as a means for clinicians to better understand, and then address, patient suffering. After developing this questionnaire, this cohort of researchers went on to design a brief psychotherapy model to

address dignity-related suffering (Chochinov et al., 2011; Kumar, Morse, Zemenides, & Jenkins, 2012).

Dignity Therapy uses trained therapists for one to two sessions to explore a patient's personal history and discuss experiences and stories that are most meaningful. Therapists encourage patients to discuss lessons they have learned and what they would like to communicate to others. The protocol includes questions like "Tell me a little about your life history; particularly the parts that you either remember most or think are the most important?" "When did you feel most alive?" And, "What are your hopes and dreams for your loved ones?" These sessions are audiotaped and transcribed for patients. Patients then have the opportunity to look over and edit their transcripts. The final product is a 'generativity document,' which patients can leave as part of their legacy. When compared to usual care, Dignity Therapy did not show any significant difference from usual care, though researchers assert that patients in the research group were more likely to describe the intervention as helpful Chochinov et al., 2011. They also posit that the generativity document may offer an important tool in supporting bereaved family members.

The specific protocol of Dignity Therapy may be appropriate for certain patients who are interested and able to participate, but the idea of promoting feelings of meaning, purpose and sense of self are important in hospice social work. Legacy tools can also offer an important outlet for patients. They may be formal or informal, written, recorded, or take another less traditional form. The development of a legacy tool can offer an opportunity for a patient to reconnect to a more vital sense of self and also offer an alternate means to communicate with loved ones at a time when conversations may be difficult due to intense emotion.

Chochinov offers a final intervention that may be used by any hospice practitioner, but would certainly be useful for social workers. The “Patient Dignity Question” asks “What do I need to know about you as a person to give you the best care possible?” This question, designed to recognize an individual’s personhood, was positively endorsed by 99% of patient respondents (Chochinov et al., 2015). Hospice social workers might ask this question when meeting patients and working to develop a therapeutic relationship to introduce, or reinforce, the patient-centered approach to care.

### **Meaning-Centered Psychotherapy**

Meaning-Centered Psychotherapy is an intervention developed through research into the “desire for hastened death” (Breitbart et al., 2010; Breitbart et al., 2012; Breitbart et al., 2015). This therapeutic model is designed to address spiritual wellbeing and existential distress. This psychotherapy was piloted as a group model for patients with advanced cancer (Breitbart et al., 2010). Responding to the barriers very ill patients might face in attending group therapy sessions, researchers developed a similar model for individual therapy (Breitbart et al., 2012). In each of three studies, participants were recruited through outpatient oncology clinics.

The individual approach would be most applicable for home hospice social workers. Individual Meaning-Centered Therapy is a seven-session, goal-directed model. The first session goal is to “Learn patient’s cancer story and introduce concepts and sources of meaning.” The second session goal is to “Develop a general understanding of one’s sense of identity and the impact cancer has made upon it.” These goals continue with exploration of legacy, limitation, attitude towards suffering, creativity, responsibility, sources of meaning, and hopes for the future (Breitbart et al., 2012). A

randomized controlled trial found improved spiritual wellbeing, which comprises both sense of meaning and faith, quality of life, symptom burden, and symptom-related distress when compared to a control group receiving therapeutic massage. These domains were measured using the Functional Assessment of Chronic Illness Therapy, the Spiritual Well-Being Scale, the McGill Quality of Life Questionnaire, the Hospital Anxiety and Depression Scale, the Beck Hopelessness Scale, and the Memorial Symptom and Assessment Scale. Results showed no difference from the control group in outcomes for anxiety, depression, or hopelessness. The authors note the challenge in selecting a control group therapy, and their choice of therapeutic massage may not have offered a comparable style of intervention (Breitbart et al., 2012).

A recent study of Meaning-Centered Group Psychotherapy, showed more comprehensive improvements related to spiritual wellbeing, quality of life, depression, hopelessness, “desire for hastened death,” and symptom distress compared to a control group receiving supportive group psychotherapy (Breitbart et al., 2015). Further research is needed, but thus far, Meaning-Centered Psychotherapy appears more effective with groups than with individuals.

Participants in these studies were all outpatients, and likely, higher functioning than home hospice patients. Despite the discussed limitations, some components of the model may still offer useful direction for hospice social workers. Given its focus on spiritual well being, Meaning-Centered Psychotherapy may offer a framework for clinical interventions with individuals expressing existential suffering. In many cases, and for many physical and environmental reasons, a hospice patient may not be able to engage in a formal seven-session therapy. This may also be true for the social workers, whose

responsibilities extend far beyond patient psychotherapy. However, the weekly goals can offer social workers areas to explore and direction in how to address the extremely challenging domain of existential suffering.

There are notable commonalities in the two psychotherapies developed in response to researching the “desire for hastened death.” Both Dignity Therapy and Meaning-Centered Psychotherapy emphasize positive life review through connecting to one’s identity as a well person and recognizing sources of pride and past accomplishments. Both approaches encourage patients to identify what is meaningful to them in their past, present and future. Each therapy also includes a legacy project, which empowers a patient to share knowledge and guidance in a permanent form that will remain for future generations. These therapies individually provide hospice social workers specific questions, topics, and clinical activities that can be integrated into practice. When considered together, Dignity Therapy and Meaning-Centered Psychotherapy direct clinical awareness to the importance of meaning and purpose for patients. Neither intervention is adequate to address the spectrum of factors that may contribute to the “desire for hastened death,” but each offers insight and direction, and can better equip social workers to address these needs.

## **Chapter 10: Implications for Future Social Work Practice**

A terminally ill individual's "desire for hastened death" is a complex construct, pervasive in hospice care. Supporting patients through their struggles presents an ongoing challenge for all hospice clinicians, but particularly the social workers responsible for addressing mental health needs. "Desire to die" expressions represent ways for patients to communicate their distress, and may be motivated by a host of physical, psychological, spiritual, social, and environmental factors. The breadth of these domains of suffering creates a profound clinical challenge for hospice social workers already limited by the scope of their professional roles, and, often, lack of resources.

These clinicians need more education about patient "desire for hastened death." Current professional understanding of this concept is inconsistent. Hospice social workers need training to develop a comprehensive understanding of "desire for hastened death." It is imperative for clinicians to depathologize patient "desire to die statements," which should be interpreted as expressions of distress, unrelated to suicide.

The multifactorial influences on patient desires make it impossible to identify a single therapeutic approach that could effectively address such diverse patient needs. Furthermore, the unpredictable nature of terminal illness, and hospice social work, present barriers in the provision of formal therapeutic interventions. Social workers would be better prepared to address these needs through the ability to complete a "biopsychosocial-spiritual" assessment focused on factors contributing to the "desire for hastened death." Clinical practice should also recognize the importance of themes like dignity, meaning, and legacy. Building on this foundation, social workers should have

knowledge of specific therapeutic tools that they can integrate in the development of informed, dynamic interventions with patients who express a “desire for hastened death.”



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## Appendix A: Informed Consent

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**Title of the Research Study:** The Penn Home Hospice Study

**Protocol Number:** 821531

**Principal Investigator:** Zvi Gellis PhD, SSW, Castor Building, 3701 Locust Walk, Philadelphia, PA 19104; 215-746-5487; zgellis@upenn.sp2.edu

**Co-investigator:** Sarah Wichman DSW-Candidate, 39 Broadway, Ste 200 New York, NY 10003; 917-685-7344

**Emergency Contact:** Sarah Wichman DSW-Candidate, 39 Broadway, Ste 200 New York, NY 10003; 917-685-7344

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You are being asked to take part in a research study. This is not a form of treatment or therapy. It is not supposed to detect a disease or find something wrong. Your participation is voluntary which means you can choose whether or not to participate. If you decide to participate or not to participate there will be no loss of benefits to which you are otherwise entitled. Before you make a decision you will need to know the purpose of the study, the possible risks and benefits of being in the study and what you will have to do if decide to participate. The research team is going to talk with you about the study and give you this consent document to read. You do not have to make a decision now; you can take the consent document home and share it with friends, family doctor and family.

If you do not understand what you are reading, do not sign it. Please ask the researcher to explain anything you do not understand, including any language contained in this form. If you decide to participate, you will be asked to sign this form and a copy will be given to you. Keep this form, in it you will find contact information and answers to questions about the study. You may ask to have this form read to you.

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### What is the purpose of the study?

The purpose of the study is to learn more about patient perspectives about their experience of illness and end of life decisions in the home hospice context. This study is being conducted for the interviewer's doctoral dissertation.

### Why was I asked to participate in the study?

You are being asked to join this study because you are an adult home hospice patient who is able and willing to speak about your experiences. You were identified as someone who could offer insight into your experience, and you expressed interest in participating.

### How long will I be in the study?

You will be asked to participate in a single, one-time interview that is expected to last 30-60 minutes.

**Where will the study take place?**

This study will take place at your current residence. The date and time of the interview will be scheduled at your convenience.

**What will I be asked to do?**

You are being asked to participate in a one-time in-depth interview about your perspectives on your illness experience while receiving home hospice care. This interview should take 30-60 minutes to complete.

**What are the risks?**

The risks for involvement in this study are minimal. However, you may feel emotionally uneasy about certain questions. You have the right not to answer any questions that you do not feel comfortable answering.

**How will I benefit from the study?**

There is no benefit to you. However, your participation could help us understand more about the experience of being a home hospice patient. In the future, information from this study may help hospice social workers better understand and address the needs of home hospice patients.

**What other choices do I have?**

Your alternative to being in the study is to not be in the study.

**What happens if I do not choose to join the research study?**

You may choose to join the study or you may choose not to join the study. Your participation is voluntary.

There is no penalty if you choose not to join the research study. You will lose no benefits or advantages that are now coming to you, or would come to you in the future. Your social worker will not be upset with your decision.

If you choose not to volunteer in the research study, your current services will continue.

**When is the study over? Can I leave the study before it ends?**

Your participation in the study will consist of one 30-60 minute interview. When the interview is complete your participation will also be complete. You have the right to terminate the interview prior to completion if needed.

You have the right to drop out of the research study at anytime during your participation. There is no penalty or loss of benefits to which you are otherwise entitled if you decide to do so. Withdrawal will not interfere with your future care.

If you no longer wish to be in the research study, please contact Sarah Wichman, at 917-685-7344 to inform of your withdrawal from the study.

**How will confidentiality be maintained and my privacy be protected?**

We will do our best to make sure that the personal information obtained during the course of this research study will be kept private. However, we cannot guarantee total privacy. Your personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used.

This consent form is the only material with your name, and it will be separated from audiotapes and interview transcripts. Your interview will be audiotaped for transcription purposes only. The audio recording will then be destroyed. Audiotapes and transcripts will be catalogued by number. All study materials will be kept in locked drawers in a locked office. The interviewer is the only person who has a key and access to this office.

**Will I have to pay for anything?**

There is no cost associated with your participation in this study.

**Will I be paid for being in this study?**

You will not be paid for your participation in this study. Your participation is appreciated.

**Who can I call with questions, complaints or if I'm concerned about my rights as a research subject?**

If you have questions, concerns or complaints regarding your participation in this research study or if you have any questions about your rights as a research subject, you should speak with the Principal Investigator listed on page one of this form. If a member of the research team cannot be reached or you want to talk to someone other than those working on the study, you may contact the Office of Regulatory Affairs with any question, concerns or complaints at the University of Pennsylvania by calling (215) 898-2614.

**Statement of your consent**

I have read the above description of this research study. I have been informed of the risks and benefits involved, and all my questions have been answered to my satisfaction. Furthermore, I have been assured that any future questions I may have will also be answered by a member of the research team. I voluntarily agree to take part in this study.

☐ Yes, I give my consent to participate in the study.

☐ No, I am not willing to participate in the study.

**Statement of your consent to be audio taped**

☐ I understand that audio recordings will be taken during the study.

☐ I understand that audio recordings will be destroyed following transcription, and that no identifying information will be included in the transcription.

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When you sign this document, you are agreeing to take part in this research study. If you have any questions or there is something you do not understand, please ask. You will receive a copy of this consent document.

Signature of Subject

Print Name of Subject

Date

## **Appendix B: Interview Guide**

(This interview guide was completed with the assistance of Dr. Tracy Schroepfer, who is a consultant on this project, and portions of were adapted, with permission, from Dr. Schroepfer's previous work).

Thank you very much for allowing me to meet with you today. I appreciate your willingness to speak with me and answer questions. With your permission, I would like to record our discussion so that I can make sure I don't miss anything. I want to reassure you that everything you say is confidential.

### *Completion of Consent Form*

#### Demographics

Age:

Gender:

Marital Status:

Race/Ethnicity:

Religion/Spiritual Affiliation:

Educational Level (How many years of school have you completed?):

Employment (What kind of work did you do?):

Primary Diagnosis:

Time on home hospice:



I would like to talk to you about your feelings and experience related to your illness.

Some questions are personal and may be difficult to discuss. Please let me know if you feel uncomfortable at any time.

6) Would you tell me the main ways that your illness has affected your everyday life?

7) Has anyone discussed the likely outcome of your illness with you?

*If yes:* What do you know about your condition?

*If no:* What is your sense about what's going to happen?

*If patient does not appear to have appropriate understanding of his/her illness, skip to question 4.*

8) Sometimes, when people are facing a life-limiting illness, it can be natural for them to have thoughts of hastening their death. Have you ever had thoughts like this?

a) *If yes:*

i) Would you tell me more about these thoughts? About how often do you find yourself thinking about this?

- What is happening in your mind when these thoughts arise?

ii) Would you tell me about any specific reasons or factors that have led you to consider this?

iii) Have you spoken to anyone else about this?

iv) Have you ever thought about how you might to hasten your death? If so, what have you thought about? Are you pursuing this currently?

b) *If no: move to question 4.*

9) I want to ask about your experience receiving hospice care at home.

- a) Are there any parts your home hospice experience that have been especially stressful for you? Would you tell me about them?
  - b) Are there any parts of your home hospice experience that have been positive for you? Would you tell me about them?
- 10) Before we conclude our discussion, are there any issues or concerns about your illness experience that we did not cover and you would like to bring up now?

Please feel free to raise any concerns, offer feedback, or ask questions.



The UPenn School of Social Policy and Practice is  
partnering with MJHS Hospice for...

## **The Penn Home Hospice Study: Patient Perspectives**

- Are you enrolled in MJHS Hospice?
- Are you over 18?

**We are looking for volunteers to  
participate in a research study about  
their home hospice experiences.**

Study volunteers will be asked to participate in one  
30-60 minute in-person interview. Researchers will  
be available to meet participants at their homes.

Interested? Please complete the enclosed form, or call...

Primary Investigator:  
Sarah Wichman, LMSW, DSW-Candidate: 917-685-7344

## Appendix D: Patient Recruitment Letter



Dear \_\_\_\_\_,

I am writing to tell you about the Penn Home Hospice Study, in partnership with MJHS Hospice. The purpose of this research study is to learn more about individual experiences as a home hospice patient. We are seeking hospice patients who are willing to participate in a one-time interview and share their perspectives.

If you are interested in learning more, please review the enclosed information, complete the brief form, and mail it back to us in the pre-paid envelope. You can also call us at 917-685-7344.

It is important to know that this letter is not to tell you to join this study. It is your decision. Your participation is voluntary. Whether or not you participate in this study will have no effect on your relationship with MJHS Hospice as a patient. You do not have to respond if you are not interested in this study. If you do not respond, no one will contact you.

Thank you for your time and consideration.

Sincerely,

Sarah Wichman, LMSW, DSW-Candidate

**Penn Home Hospice Study: Patient Perspectives**

**Please complete this form and return in the pre-paid envelope provided**

☐

I am interested in learning more about this study.  
Please contact me using the following information:

Name: \_\_\_\_\_

Telephone(s):  
\_\_\_\_\_

Best time and day to call:  
\_\_\_\_\_

Email: \_\_\_\_\_

## **Appendix E: Social Worker Referral Flyer**



# **Penn/MJHS Home Hospice Study**

## **Social Work Referral Information**

**Do you have home hospice patient(s) that fit(s) this description?**

### **Inclusion Criteria**

- Patients must be enrolled in MJHS Hospice Home Care services.
- Patients must be over 18.
- Patients must be English-speaking.
- Patients must have made some expression of a “desire to hasten death.”
- Patients must be cognitively able to consent to, and, participate in, an in-depth interview. Patient participation is voluntary and he or

she must have demonstrated willingness to discuss end of life issues.

- Patients must be verbal and physically able to engage in extended conversation.
- Patients must have been enrolled in hospice for a minimum of two weeks.

### **Exclusion Criteria**

- Patients who have cognitive impairments and lack capacity to sign consent forms.
- Patients who may be emotionally vulnerable and therefore unable to tolerate the discussion of sensitive topics.
- Patients with communication difficulties such as moderate to severe hearing impairments or speech impediments.
- Patients who have a history of suicide attempts, or are actively suicidal.

**To make a referral, email your patient's name and MJHS ID**

**number:**

**Sarah Wichman**

**swichman@mjhs.org**

**917-685-7344**

**THANK YOU!!!**

**Your referrals make this study possible!**



## **Appendix F: Recruitment Phone Call Script**

### Initial Phone Call Script

(Patients will have recruitment materials and be asked to reach out to the PI if interested in learning more about participation in this study).

SW: Hello (patient's name) this is Sarah Wichman, I am a researcher with the Penn Home Hospice Study. Thank you for your time and your interest in this study. Did you have the opportunity to read through the materials about the study?

*If patient says no, the PI will offer a brief overview of the information in the recruitment letter and flyer. The description will go slowly and allow opportunities to confirm the patient's understanding and answer questions:*

PI: This study is seeking volunteers for a one-time interview that will take place at your home. The interview is expected to last 30-60 minutes. This interview will explore your individual experience with hospice care at home.

PI: Do you have any questions or concerns about this study?

*If patient says yes, PI will address these questions.*

*If no, PI will highlight important points about participation and pause throughout to discuss and clarify points as needed:*

PI: There are a few things that I want to highlight about participating in this study:

- The goal of this study is to learn about your experience receiving hospice services at home.
- Your participation is entirely voluntary. It will have no impact on your current or future care. We respect your decision to participate, or not to participate.
- Your privacy is a priority, and all possible means will be used to ensure your privacy.
- Risks related to participation are minimal, but the researcher will ask questions about your illness experience, which may cause some people to feel uneasy. Participants have the right to decline to answer any interview question.
- Even if you initially agree to participate, you have the right to withdraw at any time before, during, or after the interview.
- The interview will take place at your home at your convenience.
- The interviewer is affiliated with MJHS hospice and will collaborate with your team if you have any needs arise during the interview.
- There is no payment for participation.
- In the future, information from this study may help hospice social workers better understand and address the needs of home hospice patients.

*The PI will discuss and clarify all points with potential participant. If he or she agrees to volunteer, the PI will schedule a time for an interview.*

*Some patients may wish to take time to decide, or discuss with caregivers before volunteering. If so, the PI will schedule a follow up phone call. The PI will also be available to answer questions from any family members, with the permission of the patient.*

*If the patient declines, the PI will thank that person for his or her time and wish them well.*

*All patients will have researcher contact information and know that they may follow up with any additional questions.*

## **Appendix G: Mini Mental State Exam**

“MINI-MENTAL STATE” (Folstein, Folstein, & McHugh, 1975)

### **ORIENTATION**

- ( ) What is the (year) (season) (date) (day) (month)?
- ( ) Where are we: (state) (county) (town) (hospital) (floor).

### **REGISTRATION**

- ( ) Name 3 objects: 1 second to say each. Then ask the patient all 3 after you have said them. Give 1 point for each correct answer. Then repeat them until he learns all 3. Count trials and record.  
Trials

### **ATTENTION AND CALCULATION**

- ( ) Serial 7's. 1 point for each correct. Stop after 5 answers. Alternatively spell “world” backwards.

### **RECALL**

- ( ) Ask for the 3 objects repeated above. Give 1 point for each correct.

### **LANGUAGE**

- ( ) Name a pencil, and watch (2 points)
- Repeat the following “No ifs, ands or buts.” (1 point)
- Follow a 3-stage command:  
“Take a paper in your right hand, fold it in half, and put it on the floor” (3 points)
- Read and obey the following:  
CLOSE YOUR EYES (1 point)
- Write a sentence (1 point) Copy design (1 point) Total score
- ASSESS level of consciousness along a continuum  
Alert Drowsy Stupor Coma

## **INSTRUCTIONS FOR ADMINISTRATION OF MINI-MENTAL STATE EXAMINATION**

### **ORIENTATION**

- (1) Ask for the date. Then ask specifically for parts omitted, e.g., “Can you also tell me what season it is?” One point for each correct.
- (2) Ask in turn “Can you tell me the name of this hospital?” (town, county, etc.). One point for each correct.

### **REGISTRATION**

Ask the patient if you may test his memory. Then say the names of 3 unrelated objects, clearly and slowly, about one second for each. After you have said all 3, ask him to repeat them. This first repetition determines his score (0-3) but keep saying them until he can

repeat all 3, up to 6 trials. If he does not eventually learn all 3, recall cannot be meaningfully tested.

#### ATTENTION AND CALCULATION

Ask the patient to begin with 100 and count backwards by 7. Stop after 5 subtractions (93, 86, 79, 72, 65). Score the total number of correct answers.

If the patient cannot or will not perform this task, ask him to spell the word “world” backwards. The score is the number of letters in correct order. E.g. dlrow = 5, dlorw = 3.

#### RECALL

Ask the patient if he can recall the 3 words you previously asked him to remember. Score 0-3.

#### LANGUAGE

*Naming:* Show the patient a wrist watch and ask him what it is. Repeat for pencil. Score 0-2.

*Repetition:* Ask the patient to repeat the sentence after you. Allow only one trial. Score 0 or 1.

*3-Stage command:* Give the patient a piece of plain blank paper and repeat the command. Score 1 point for each part correctly executed.

**Reading:** On a blank piece of paper print the sentence “Close your eyes”, in letters large enough for the patient to see clearly. Ask him to read it and do what it says. Score 1 point only if he actually closes his eyes.

**Writing:** Give the patient a blank piece of paper and ask him to write a sentence for you. Do not dictate a sentence, it is to be written spontaneously. It must contain a subject and verb and be sensible. Correct grammar and punctuation are not necessary.

**Copying:** On a clean piece of paper, draw intersecting pentagons, each side about 1 in., and ask him to copy it exactly as it is. All 10 angles must be present and 2 must intersect to score 1 point. Tremor and rotation are ignored.

Estimate the patient’s level of sensorium along a continuum, from alert on the left to coma on the right.